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DOCTORAL THESIS

Exploring how nurses and people with bowel disease discuss physical activity

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Exploring how nurses and people with bowel disease discuss physical activity

By

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Submitted in total fulfilment of requirements of the degree of

Doctor of Philosophy (PhD)

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Abstract

People with bowel disease, namely bowel cancer, ulcerative colitis, and Crohn's disease benefit physically and psychologically from participating in exercise and physical activity. Exercise also has the potential to reduce the risk of other diseases and comorbidities. Unfortunately, it appears that people with bowel disease are insufficiently active. As individuals with bowel disease interact with different healthcare professionals it is possible that they may receive physical activity advice during their consultations. However, how and the context within which this advice occurs is mostly unknown.

The thesis encompasses three distinct studies that contribute to the exploration of physical activity discussions for people with bowel disease. An inductive thematic analysis of 96 discussions on a public online forum identifies the role of exercise for people with bowel disease and the ways in which they discuss exercise among themselves. This is followed by semi-structured interviews that explore the experience of physical activity counselling with 21 people with bowel disease. Finally, a nursing perspective is gathered through semi-structured interviews with 15 nurses specialising in bowel surgery care.

Results indicate that exercise plays a positive role for those affected with bowel disease; however, physical activity counselling among nurses appeared lacking. Internet forum discussions highlighted the positive experience many people with bowel disease had through participating in exercise activities and discussing exercise among themselves. The semi-structured interviews reiterated the positive role of exercise for people with bowel disease, but concluded that experiencing a lack of physical activity counselling resulted in many unmet needs. The nursing perspective supported the findings that current physical activity counselling practices for people with bowel disease do not meet patient needs. However, the nurses were eager to improve their practices.

Declaration

This thesis is submitted to Bond University in fulfilment of the requirements of the degree of Doctor of Philosophy (PhD).

This thesis represents my own original work towards this research degree and contains no material that has previously been submitted for a degree or diploma at this University or any other institution, except where due acknowledgement is made.

Alicia B Olsen

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Publications

Poster Presentations

Hi, who's been exercising? Investigating how colorectal cancer survivors discuss exercise and physical activity within online discussion forums. Presented at 2014 Gold Coast Health and Medical Research Conference

Nurses experience of discussing exercise and physical activity with patients recovering from bowel disease surgery. Presented at 2016 Gold Coast Health and Medical Research Conference

Oral Presentation

What about exercise? How physical activity is discussed online among colorectal cancer patients. Presented at 2014 Australasian Society for Behavioural Health and Medicine 12th Annual Scientific Conference

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Puhlinger, P. G., **Olsen, A.**, Climstein, M., Sargeant, S., Jones, L. M., & Keogh, J. W. (2015). Current nutrition promotion, beliefs and barriers among cancer nurses in Australia and New Zealand. *PeerJ*, 3, e1396.

Ethics Declaration

The research associated with this thesis received ethics approval from the Bond University Human Research Ethics Committee, under reference numbers RO 1651, RO 1961 and RO-1882.

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Abbreviations

ACSM – American College of Sports Medicine

AHRQ – Agency for Healthcare Research

CD – Crohn’s Disease

COPD – Chronic Obstructive Pulmonary Disease

FSS – Fatigue Severity Scale

fVAS – Fatigue Visual Analogue Score

GPs – General Practitioners

HADS – Hospital Anxiety and Depression Scale

IBD – Inflammatory Bowel Disease

ITA – Inductive Thematic Analysis

MASS – Memorial Symptom Assessment Scale

NPAGA – National Physical Activity Guidelines of Australia

QOL – Quality of Life

UC – Ulcerative Colitis

Chapter 1

Bowel disease and physical activity: introducing the research

1.1 Introduction

Exercise is known to be beneficial for personal health. People invest in healthy behaviours such as exercise or physical activity with the notion of maintaining health and reducing the risk of developing illness or disease. Some individuals may engage in social media or other platforms to motivate, encourage, or learn more about the benefits of exercise in maintaining health and preventing the development of chronic disease. However, after developing an illness or disease, questions about the relevance of exercise for health can arise and what seems a relatively straightforward relationship between exercise and health can become more complicated.

My Master's research project raised the idea that illness or disease can cause people to question the appropriateness of exercise to maintain health. The research project investigated the effects of physical activity on levels of fatigue and nervous system function in women diagnosed with breast cancer (Olsen, 2012). During data collection, the women shared stories about the benefits they noticed from becoming physically active. The women also shared the frustrations they had with the limited information about exercise they received from their doctors, surgeons, nurses, and other members of their care team. This lack of information caused them to question their decisions about whether to engage in physical activity, even though they enjoyed it. They described feeling concerned that they might injure themselves, or wondered if exercise might have an unwanted effect on their diagnosis and survivorship. Therefore, they all believed that exercise should have been discussed in relation to their diagnosis and as part of a survivorship care plan because they would have felt more at ease engaging in exercise following their cancer diagnosis. With this knowledge, together with understanding the effects that limited physical activity counselling had on disease management and psychological well-being, the next logical step in research development was to explore this phenomenon in more detail.

Extensive research confirms the benefits of exercise for people with cancer (Lee W. Jones & Demark-Wahnefried, 2006; Mishra, Scherer, Snyder, Geigle, & Gotay, 2014) including the benefits of exercise for those with bowel cancer (Courneya & Friedenreich, 1997; Devin et al., 2016). However, with specific relation to exercise or physical activity counselling, it became apparent that counselling specific to bowel cancer was absent;

identifying a gap in knowledge. It was during a presentation at a local stoma association about this research to recruit potential bowel cancer participants, that it became clear that people with diseases of the bowel other than cancer, including Crohn's disease and ulcerative colitis (collectively known as Inflammatory Bowel Disease (IBD)) were also interested in exercise and expressed interest in learning about exercise from members of their care team. The interest of others led to a search of the literature for information about the benefits of exercise for people with IBD, as well as information regarding physical activity counselling relating to this condition. As with bowel cancer, the information about the benefits of exercise for individuals with IBD was present in the literature (Bilski, Brzozowski, Mazur-Bialy, Sliwowski, & Brzozowski, 2014; Perez, 2009), but guidelines or knowledge surrounding IBD-related physical activity counselling were lacking. Therefore, this programme of research included people with IBD, as well as those with bowel cancer.

Other commonalities exist between IBD and bowel cancer, such as the experience of stigma associated with disease of the bowel (Phelan et al., 2013; Taft & Keefer, 2016), impact on quality of life (QOL), (Tung et al., 2016; Ueno, Nakayama, Hagiwara, Kurimoto, & Hibi, 2016) and treatment via surgery (Baumgart & Sandborn, 2007; Brenner, Kloor, & Pox, 2014). Thus, many people with either IBD or bowel cancer might experience similar barriers to discussing exercise and participating in physical activity in any capacity.

The following two sections will introduce and briefly discuss the aetiology, symptomology, and potential benefits of exercise for people with bowel cancer followed by IBD.

1.2 Bowel cancer

Bowel cancer includes cancers of the colon and rectum, and is the second most common cancer diagnosed in Australia (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2010). People diagnosed with IBD for greater than 10 years are suggested to be at an increased risk of developing bowel cancer (Mozdiak, O'Malley, & Arasaradnam, 2015; Solomon & Schnitzler, 1998; Z. H. Wang &

Fang, 2014). Other risks factors for bowel cancer include obesity, cigarette smoking, and sedentary lifestyle (Johnson et al., 2013; Qasim & O'Morain, 2010). People complaining of rectal bleeding, and/or abdominal pain in conjunction with unexplained exhaustion are recommended for bowel cancer screening (Rasmussen et al., 2015).

A bowel cancer diagnosis is defined with different stages and sub-stages according to the extent of lymph node involvement, the presence of distant metastases, and local tumour invasion depth. Medical intervention options include surgery, chemotherapy, and radiotherapy, and are dependent on the stage and locale of disease (Brenner et al., 2014). Bowel cancer survivors report a range of symptoms as a result of their treatment or disease. These symptoms include cancer-related fatigue (Thong et al., 2013), declines in physical fitness, and reduced QOL (Jensen, Houborg, Nørager, Henriksen, & Laurberg, 2011; Sánchez-Jiménez et al., 2015). Fitness and global health status of bowel cancer survivors are reported to be significantly less than healthy age and gender matched controls (Sánchez-Jiménez et al., 2015). Some symptoms are noted to last well past diagnosis with fatigue reported to be greater in bowel cancer survivors compared to healthy age and gender matched controls five or more years post-diagnosis (Thong et al., 2013). Therefore, long-term bowel cancer survivors may continue to suffer from symptoms of their disease many years after their diagnosis, even if their cancer appears to be in remission.

Exercise is known to improve the symptoms associated with bowel cancer and treatment-related side-effects. For example, an 8-week home-based resistance exercise program significantly improved mobility, fatigue, and sleep quality in people with bowel cancer compared to the non-exercise group (Cheville et al., 2013). Furthermore, people with bowel cancer who scored low on a fitness test (6-minute walk) had poor QOL and greater depression scores compared to people with bowel cancer who scored higher on the fitness test (Lee et al., 2015). Thus, improvements in physical fitness and increasing exercise levels are speculated to lead to improvements in symptoms, such as QOL and severity of depression.

1.3 Inflammatory bowel disease

IBD is an inflammatory disease of the digestive tract. Ulcerative colitis is located in the colon only, while Crohn's disease can affect the entire gastrointestinal tract, from the mouth to the anus (Baumgart & Sandborn, 2007). The exact aetiology of IBD is unidentified and the precise pathogenesis has yet to be established (Corridoni, Arseneau, & Cominelli, 2014). However, research speculates that environmental and immunity factors may lead to the development and onset of IBD (Baumgart & Sandborn, 2012; Corridoni et al., 2014). Race, age, and genetics are also suspected risk factors (Twedell, 2008).

IBD consists of two stages of disease, relapse and clinical remission. During relapse, people can experience a range of symptoms including diarrhoea, pain, fatigue, and weight loss (Becker et al., 2015; Norton, Thomas, Lomax, & Dudley-Brown, 2012; Twedell, 2008). Clinical remission is defined as the absence of any symptoms (Teruel, Garrido, & Mesonero, 2016); however, IBD may still affect the psychological functioning of people in this stage (Lix et al., 2008). Therefore, symptoms associated with IBD appear to be a constant influence on peoples' lives and well-being regardless of disease stage.

Symptoms of IBD are currently managed surgically or with medication. Recent preliminary evidence suggests that exercise may also help manage certain symptoms of IBD, such as poor QOL (Bilski et al., 2014) and fatigue (Beck, Bager, Jensen, & Dahlerup, 2013). For example, a supervised 30-minute moderate intensity running program performed three times per week for 10 weeks was found to improve the social well-being of people with IBD compared to usual care (Klare et al., 2015). Furthermore, exercise was reported to be generally well tolerated by individuals with IBD, with 66% (n=607/918) to 82% (n=186/227) reporting participating in exercise at least one day per week. (Chan, Robbins, Rogers, Clark, & Poullis, 2014; DeFilippis et al., 2016) Such outcomes have led to requests for additional investigations to explore the potential benefits of exercise for people with IBD (Bilski et al., 2014).

1.4 Current exercise recommendations for people with bowel disease

The American College of Sports Medicine (ACSM) defines exercise as requiring structured a repetitive movement that results in improved fitness, while physical activity includes all activities that require physical work (Moore, Durstine, Painter, & Medicine, 2016). However, as these terms are used interchangeably within the literature, they will continue to do so throughout this research program.

Some exercise recommendations exist for people with bowel cancer and IBD. Such recommendations contain similarities and differences within and between the two conditions from a variety of health organisations. This section discusses the current exercise recommendations for people with bowel cancer followed by the exercise recommendations for individuals with IBD.

People with bowel cancers are recommended by the ACSM to engage in aerobic, resistance, and flexibility exercise on most days of the week (Thompson, Arena, Riebe, & Pescatello, 2013). These guidelines specifically involve exercising at a mild intensity for 60 minutes for aerobic exercise, 8-12 repetitions or resistance exercise, and to stretch, holding each position for approximately 30 seconds. These guidelines were developed for all people with chronic diseases. The Agency for Healthcare Research and Quality (AHRQ) of the United States of America generally agrees that exercise is safe for cancer patients; however, the ACSM recommends that patients currently undergoing treatment for cancer modify their exercise regimen (Schmitz et al., 2010), such as exercising at a lower intensity or for shorter bouts (Rock et al., 2012). National Physical Activity Guidelines for Adults (NPAGA), from the Australian Department of Health and Ageing, recommend being active at a moderate intensity for at least 30 minutes on most days of the week (Department of Health and Ageing, 2013).

Exercise or physical activity guidelines for people with IBD vary internationally. For example, Canadian standard general physical activity guidelines suggest at least 60 minutes of low-intensity exercise per day, while similar guidelines in Australia recommend 150 to 300 minutes of moderate intensity per week (Brown, Bauman, Bull, & Burton, 2013). However, these guidelines are not unique to people with IBD.

Furthermore, people with IBD are recommended by the ACSM to follow the exercise recommendations for people with chronic disease as previously described, but any necessary modifications should be made based on any limitations and contraindications experienced during an exercise bout (Moore et al., 2016). This recommendation applied to all chronic conditions, not IBD specifically, and is not substantiated by any specific research for this condition. To date, there is only one set of exercise recommendations (Table 1.1) specifically targeted at IBD patients (Ball, 1998). These guidelines were developed utilising the ACSM exercise guidelines as a template. To complement these guidelines, the author outlined special considerations, such as the advice that high intensity exercise may exacerbate symptoms of IBD, based on the literature surrounding exercise and gastrointestinal function. Other special considerations suggest that people with IBD be particularly aware of their hydration levels as identified by the signs and symptoms of dehydration. Concerns regarding hydration were addressed based on findings suggesting individuals with IBD are at greater risk for dehydration caused by the symptoms of IBD such as loose stools or diarrhoea.

Table 1.1

Exercise guidelines for people with IBD

Mode	Intensity	Frequency	Duration
Aerobic, endurance exercise using large muscle groups	50 - 85% of VO ₂ max or 60 - 90% of heart rate max	3 – 5 days per week	20 – 60 minutes
Strength training	Moderate intensity	2 days per week	8 – 10 separate exercises using major muscle groups 8 – 12 repetitions of each set

Note. From "Exercise guidelines for patients with inflammatory bowel disease," by Edna Ball, 1998, *Gastroenterology Nursing*, 21(3), p. 110.

1.5 Are people with bowel disease aware of the benefits of exercise and exercise recommendations?

As mentioned previously, exercise may provide some relief from bowel disease symptoms such as poor QOL, depression, or fatigue (Beck et al., 2013; Bilski et al., 2014;

Lee et al., 2015). People with bowel disease may communicate with each other in regards to their experience of living with, and managing symptoms of bowel disease. Evidence suggests that the Internet is a source of information for understanding diagnosis and treatments for people with bowel cancer (Asiedu, Eustace, Eton, & Radecki Breitkopf, 2014; Sajid, Shakir, & Baig, 2011) and IBD (Coulson, 2013). Therefore, it appears that the Internet is a common platform with which people with diseases can communicate (S. Fox & Purcell, 2010). For example, a survey of 249 people with IBD who were members of an online forum, indicated that nearly half (46.9%) accessed an online forum daily (Coulson, 2013) and were also reported to be active posters to the online community (Coulson, 2015). People with IBD embrace the ability to connect with similar others and share experiences about disease management through online interactions, while considering the community beneficial to be helping them view their disease through a positive lens.

The online platform also enabled people to receive information from similar others that healthcare professionals may not necessarily be able to provide (Hartzler & Pratt, 2011). The authors, in their content analysis of two books, authored by women with breast cancer, and messages posted by breast cancer survivors on Internet message boards, concluded that women shared their expertise in dealing with their disease in the everyday, while healthcare professionals focused heavily on ensuring patients understood disease concepts and processes. Additionally, people with chronic diseases also discussed among each other managing communication with healthcare professionals. Therefore, it appears that exploring information exchanged between people with chronic conditions online, specifically information regarding exercise and physical activity, provides an opportunity to gather insight into a particular experience of living with an illness, and how similar others and members of their healthcare team influence that experience.

Also, the current physical activity counselling practices of healthcare team members who care for patients with bowel disease remains largely unknown. People with bowel disease are likely to communicate with many healthcare professionals throughout their healthcare journey (Bennett, Munkholm, & Andrews, 2015; Brenner et al., 2014). They are the preferred source of information with 93% (N=2253) of people

living with a disease utilising their healthcare professional as their main source in asking for assistance (S. Fox & Purcell, 2010). These healthcare professionals might include general practitioners (GPs), surgeons, nurses, and disease specialists, which suggests that there are many opportunities for people with bowel disease to learn about the benefits of exercise and receive exercise recommendations. According to research, nurses are the preferred healthcare professional group that people with bowel disease wish to discuss their general health and well-being (James-Martin, Koczwara, Smith, & Miller, 2014; Lesnovska, Borjeson, Hjortswang, & Frisman, 2014; Lewis et al., 2009). People with breast, ovarian, or rectal cancer identified nursing staff as being the preferred source of information regarding diet, exercise, and weight management because patients perceived them to have more time to discuss those issues with them (James-Martin et al., 2014). Patients also saw time with nursing staff as opportunities to receive information (Van Mossel et al., 2014; Worster & Holmes, 2008) and valued the psychosocial care provided by nursing staff (Lewis et al., 2009; McCarthy, 2014). Bowel cancer patients also report communication with nurses, as opposed to oncologists, was more comfortable in the sense of the ability to ask questions more easily and being better able to understand responses (McCarthy, 2014). People with IBD reported similar findings in regards to valuing the availability of nursing staff to provide emotional support (Hernández-Sampelayo et al., 2010).

Nurses also seemed to enquire about their various cancer patients' activity levels on most or all visits along the cancer continuum (Karvinen, McGourty, Parent, & Walker, 2012; Keogh, Olsen, Climstein, Sargeant, & Jones, 2017). However, the evidence is limited regarding the extent to which nurses provide exercise recommendations or if they discuss exercise regularly with their patients, including those with bowel cancer. The evidence is also limited in regards to whether nurses provide people with IBD information about exercise. Consequently, further research should explore the depth and services provided by nurses to individuals with bowel disease (Stretton, Currie, & Chauhan, 2014).

As it has been proposed that all registered nurses be able to translate and apply research findings into their practice (Yates et al., 2002), the contexts and practices of physical activity counselling between nurses and patients should be explored to fully

appreciate the qualities of current exercise discussions with people with bowel disease. Literature suggests that exercise is beneficial for people with bowel disease and that some nurses recommend physical activity to their patients. However, how this information is conveyed to people with bowel disease is largely unknown. There seems to be less public discussion about the benefits of exercise for people with bowel disease, suggesting that they may be unaware of the potential that exercise can have in their recovery and disease management. This lack of knowledge might indicate that the physical activity counselling that bowel disease patients may have with their nurse could be the first time they hear about the benefits of exercise in conjunction with their condition. Therefore, examining the context within which physical activity counselling occurs appears to be highly necessary. How these conversations are initiated and the contexts in which they take place are important features relating to consultation discussions about exercise. Additional features of physical activity counselling may include discursive and rhetorical cues to nurses and patients as well any deficiencies and efficiencies in facilitating discussions about exercise. To inform best practice, it is important to understand the current perceived conversational practice. Therefore, this research programme will also gather intelligence on physical activity counselling that occurs between bowel disease care nurses and bowel disease patients, specifically how they were initiated, conducted, received and acted upon. The following list illustrates the primary and secondary research questions of this thesis:

Primary Research Question:

- How and in what context is exercise discussed among people with bowel disease?

Secondary Research Questions:

- How do people with bowel disease discuss exercise among themselves?
- What perceived role does exercise have for people with bowel disease?
- What are the practices and discourses of physical activity counselling?
- What are the perceptions of physical activity counselling among nursing professionals and people with bowel disease?

1.6 Overall remit of this thesis

The overall aim of this thesis is to explore physical activity counselling for people with bowel disease. Table 1.2 illustrates the studies that assisted in answering each secondary research questions. The culmination of the findings from each study resulted in answering the primary research question of this thesis.

Table 1.2

Studies examining each research question

Research Question	Study one	Study two	Study three
How do people with bowel disease discuss exercise among themselves?	X		
What perceived role does exercise have for people with bowel disease?	X	X	X
What are the practices and discourses of physical activity counselling?		X	X
What are the perceptions of physical activity counselling among nursing professionals and people with bowel disease?		X	X

This thesis will read as follows:

Chapter Two examines the literature surrounding health communication, specifically physical activity counselling, for people with bowel cancer and IBD. The literature review delivers an overview of the physical and psychosocial challenges that people with bowel disease encounter and provides an outline of the current evidence for exercise as a means of alleviating many of those challenges. The literature on physical activity counselling is then discussed to provide insight into current practices.

Chapter Three describes the theoretical foundations and qualitative methods utilised in this thesis. This chapter will present a justification for the qualitative methods and discuss the theoretical underpinnings of this thesis in relation to qualitative health communication research. The method and rationale of the analysis chosen for all the studies of this thesis are also presented.

Chapter Four reports on the first study of this thesis which addresses research questions one and two. It begins with a review of how the Internet can be utilised to

explore the lived experience of disease. A rationale for employing the Internet and its contribution to qualitative health research is explained. The ethical considerations of utilising the Internet to explore health are also discussed. An inductive thematic analysis as recommended by Braun & Clark (2006) of the interactions and communication within an online cancer support group is presented.

Chapter Five begins with a background review detailing the benefits of exercise for people with bowel disease and the rationale for applying a qualitative approach to explore the experience of exercise and physical activity counselling for people with bowel disease. The methods employed to achieve the aims of Chapter Five are described. This included semi-structured interviews, with people with bowel disease, to foster an understanding of how physical activity counselling is experienced. Semi-structured interviews created an opportunity for the researcher and the participants to explore the practices and discourses of physical activity counselling and the influences on the role of exercise and patient satisfaction with care as a result of these practices. This exploration delivered insight into physical activity counselling from the perspective of people with bowel disease and followed on from Chapter Four in regards to the benefits of exercise for people with bowel disease. This is followed by a detailed account of the results. The findings are then discussed in relation to the current literature and then summarised in the conclusion.

Chapter Six introduces a brief review detailing the role of nurses in caring for people with IBD and bowel cancer followed by an exploration of the role of nurses in exercise communication. The methods utilised to answer these research questions are explained. This included semi-structured interviews with nurses on gastrointestinal surgical wards to advance the knowledge of current physical activity counselling practices. Based on the findings from Chapter Five, it was decided that qualitative interviews would provide the same opportunity for the researcher and the participant to explore the participants' individual physical activity counselling practices and potential efficiencies and deficiencies in the participants' practice. This evaluation provided further insight into physical activity counselling for people with bowel disease and how the nurses appeared to manage their role in providing physical activity counselling with that of other healthcare professionals.

Chapter Seven combines the findings from all three studies as they related to the aim of this thesis and answers the primary research question. New discoveries that were made as a result of this thesis are also explored. The discussion reviews the role of exercise for people with bowel disease and how this role may affect the experience of physical activity counselling from a patient and nursing perspective. The perceived role of nurses to engage in physical activity counselling and the effect this had on their counselling practice is also discussed and implications for future research were made.

This Chapter provides an overview of this thesis. To begin answering the research questions, a review of what is already known about the benefits of exercise and physical activity counselling practices was necessary. The next step will consider some of the physical and psychosocial challenges faced by people with bowel disease and how exercise or physical activity relates to many of those challenges. The literature surrounding physical activity counselling will also be explored in addition to the qualitative methods that have previously examined this practice.

Chapter 2

**The effects of bowel disease, the benefits of exercise and the
current physical activity counselling practices**

2.1 Introduction

The previous chapter provided a presentation of this thesis. The introduction delivered a synopsis of the literature and presented a rationale for exploring physical activity counselling that occurs between people with bowel disease and the nurses who care for bowel disease patients. Two primary sections divide this chapter. Section One will focus on: 1) the physical and psychosocial challenges faced by people with bowel disease; 2) how physical activity may attenuate many of these physical and psychosocial symptoms; and 3) physical activity levels in bowel disease patients. Section Two will focus on the manner in which healthcare professionals may counsel their bowel disease patients to improve their physical and psychosocial health by increasing their levels of physical activity. Physical activity counselling in cancer care will be explored first, followed by a review of the literature on counselling practices in primary care. The focus on physical activity counselling in primary care was done due to the complete lack of such research in IBD. Additionally, people with IBD commonly receive follow-up care by their primary doctor. Within each of the sections on physical activity counselling, the focus will be on summarising key studies that have examined healthcare professionals' current physical activity counselling practices, barriers, and motivators. The methods utilised to explore physical activity counselling are then discussed followed by why this phenomenon requires a qualitative approach.

2.2 The physical and psychosocial challenges faced by people with bowel disease

This section will outline the physical and psychosocial challenges faced by people with bowel disease in two sections. Explored first are the physical and psychosocial challenges faced by individuals with bowel cancer followed by those challenges faced by people with IBD. Each section will briefly discuss the prevalence of disease to provide insight into the number of individuals that may suffer from the physical and psychosocial consequences of bowel disease.

2.2.1 Physical and psychosocial challenges faced by people with bowel cancer

Cancers of the rectum and colon are defined as bowel cancers for the purpose of this thesis. Bowel cancer is synonymous with colorectal cancer. Countries in Africa and South-Central Asia report lower incidences of bowel cancer, compared to Australia and New Zealand, who have the highest incidences of bowel cancer worldwide (Jemal et al., 2011). Within Australia, bowel cancer is the second most common diagnosed cancer in men and women and the third most common cause of cancer-related death for both genders (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2010). The 5-year relative survival rate, when treated early is 90%, (39% of cases) (Miller et al., 2016). However, most incidences see a 65% 5-year relative survival rate (Brenner et al., 2014; Miller et al., 2016). While these 5-year survival rates are encouraging, individuals with bowel cancer live with a wide variety of physical and psychosocial challenges.

Several risk factors for bowel disease are reported. These factors include family history, obesity, sedentary lifestyle, cigarette smoking, red meat intake, and low consumption of fruits and vegetables (Johnson et al., 2013; Keum et al., 2016; Scarpa et al., 2014). IBD is also a suggested risk factor with increased duration of IBD leading to greater risk of developing bowel cancer (Mozdiak et al., 2015; Solomon & Schnitzler, 1998; Z. H. Wang & Fang, 2014).

Bowel cancer is diagnosed in different stages and sub-stages based on the depth of the local tumour invasion, the extent of lymph node involvement, and the presence of distant metastases. (Brenner et al., 2014). Treatment for bowel cancer varies depending on the stage of the disease. Stage I and II patients, who account for about 84% of cases, and about two-thirds of Stage III cases will be treated surgically (Miller et al., 2016). Stage III patients and some Stage II patients will also receive chemotherapy to reduce the risk of recurrence. Figure 2.1 outlines the process from specialist investigation to follow-up care.

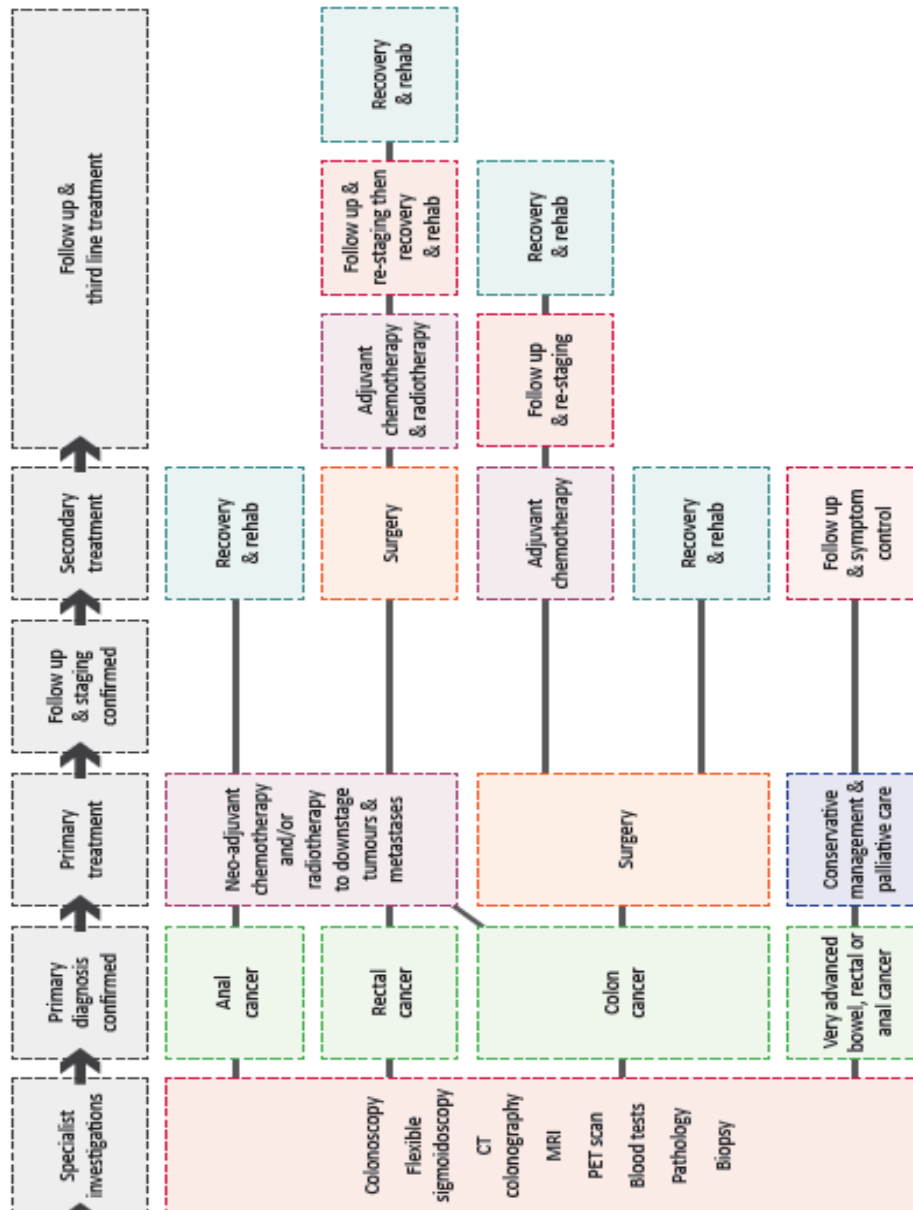


Figure 2.1. Bowel cancer treatment flowchart

Note: From Bowel Cancer- the facts, by Bowel Cancer Australia, 2017, Retrieved 04/02/2017.

During the recovery and rehabilitation stage, bowel cancer survivors experience a range of negative physical symptoms. One study suggested that the perceived, measured with the International Fitness Scale, and overall, measured by the 6-minute walk test, muscular and cardio-respiratory fitness in 23 bowel cancer survivors was significantly less than 22 matched controls (Sánchez-Jiménez et al., 2015). The International Fitness Scale, a validated short self-report scale that assesses participants' perceived level of fitness on a 5-point Likert scale, measured the participants' perceived physical fitness. The 6-minute walk test is a measure of the distance a participant walks in 6 minutes, and is a valid and reliable test of physical fitness in cancer survivors (Laskin et al., 2007). According to Sánchez-Jiménez et al. (2015), matched healthy controls walked significantly greater distances than bowel cancer survivors, indicating survivors were less fit than healthy populations. Similar results have been reported in other cancers, mostly breast (Cantarero-Villanueva et al., 2011; Peel, Thomas, Dittus, Jones, & Lakoski, 2014); highlighting the need to explore the physical challenges experienced by bowel cancer survivors. Furthermore, as bowel cancer survivors are at an increased risk of osteoporosis (Khan, Mant, Carpenter, Forman, & Rose, 2011), understanding the physical impacts of bowel cancer becomes necessary to design interventions that encourage bone health and healthy ageing.

Other physical symptoms of bowel cancer include fatigue, pain, diarrhoea, and nausea/vomiting (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2006; Cleeland et al., 2013; L. Russell et al., 2015; Walling et al., 2015). A study of 3106 cancer survivors, of which 718 of them had bowel cancer, reported that 32.9% of bowel cancer survivors suffered from fatigue, 18.5% had pain, 15.8% experienced diarrhoea, and 13.5% had nausea/vomiting (Cleeland et al., 2013). At three years follow-up 31.8%, 16.0%, 15.7%, and 15.0% of bowel cancer survivors continued to suffer from fatigue, pain, diarrhoea, and nausea/vomiting respectively. These long-term symptoms may present physical challenges to bowel cancer survivors as problems with bowel function contribute to a range of everyday challenges including delays in resuming work (Averyt & Nishimoto, 2014). Fatigue was also found by a similar study to be a significant symptom in bowel cancer survivors five or more years since diagnosis (Thong et al., 2013). Furthermore, compared to the general population, people with cancer are reported to be significantly

more fatigued (Cella, Lai, Chang, Peterman, & Slavin, 2002). Therefore, physical symptoms such as fatigue, continue to influence the lives of bowel cancer survivors many years following diagnosis.

Fatigue was indicated as the most troublesome symptom (Walling et al., 2015) and may contribute to negative psychological functioning in people with bowel cancer. Fatigued bowel cancer survivors were more likely to return higher scores on the depression subscale of the Hospital and Depression Scale (HADS) (Thong et al., 2013). For HADS, a score of eight out of a possible 21 or above is indicative of “*possible psychological disorder*” and 11 or above indicates “*probable psychological disorder*”. The findings of Thong et al. (2013) therefore suggest that those who reported feeling fatigued may also suffer from depressive symptoms. Depression in people with bowel cancer is consistent with the literature as a systematic review reported that depression was a common problem (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010) and affected 14% to 72.4% of bowel cancer survivors (Strong et al., 2007; Walling et al., 2015). Therefore, it appears that fatigue and depression are positively correlated and prevalent among individuals with bowel cancer.

Other psychological symptoms of bowel cancer included poor QOL (Arndt et al., 2006; L. Russell et al., 2015; Sánchez-Jiménez et al., 2015). However, it was reported that QOL could return to preoperative levels in bowel cancer patients (Jensen, Nørager, Sommer, Madsen, & Laurberg, 2014). The QOL of 47 bowel cancer patients before and four weeks post laparoscopic colonic cancer surgery was explored and it was reported that 1-2 weeks postoperative QOL life scores were significantly lower than preoperative levels. At four weeks following surgery, QOL scores were no longer significantly different from preoperative scores. The authors suggest that these results may have been influenced by the withdrawal of several participants prior to post examinations (n= 15). Additionally, the type of surgery may have resulted in fewer patients experiencing adverse QOL outcomes. Laparoscopic surgery is reported to provide better physical and psychological outcomes such as minimal effects on fatigue and QOL (Gorgun et al., 2015). Most studies that investigated the QOL of bowel cancer patients did not differentiate between the type of surgeries. However, a randomised controlled trial of 794 bowel cancer patients did not find a difference in QOL scores between open surgery

and laparoscopic surgery patients (Jayne et al., 2007). While significant advances in both forms of surgery may have occurred since 2007, the impact of different types of surgery on QOL in bowel cancer patients remains inconclusive.

2.2.2 Physical and psychosocial challenges faced by people with IBD

As previously defined in Chapter One, IBD comprises two separate, yet related, diseases of the digestive tract, ulcerative colitis and Crohn's disease. Although the aetiology and the pathogenesis are inconclusive (Corridoni et al., 2014), some risk factors have been associated with a greater risk of developing IBD. These risk factors include race, genetics, and age, with individuals between 15 and 35 years old at greater risk than other age groups (Twedell, 2008). People with siblings diagnosed with IBD are also at an increased risk in developing IBD. Environmental factors such as smoking (El-Tawil, 2010) and poor nutrition (Huang, Devkota, Moscoso, Chang, & Leone, 2013) were also suggested to be risk factors for developing this disease.

As outlined in Table 2.1, most people with IBD experience debilitating physical symptoms including diarrhoea, abdominal pain, nausea, and vomiting, and joint pain (Casati & Toner, 2000; Guthrie et al., 2002; Head & Jurenka, 2004; Norton et al., 2012; Twedell, 2008). A descriptive, cross-sectional study reported fatigue, bowel urgency, and diarrhoea as the most commonly reported symptoms by people with IBD (Farrell, McCarthy, & Savage, 2015). These symptoms were present regardless of disease status as bowel urgency (50.0%/83.8%), and diarrhoea (40.4%/74.6%) were indicated by both inactive (n=166) and active (n=68) disease sufferers respectively. Additionally, lack of energy was reported by 63.8% of people with inactive disease and 80.6% of people with active disease. Furthermore, lack of energy, as rated by the Memorial Symptom Assessment Scale (MASS) for IBD, was the most burdensome symptom regardless of disease status. MASS was developed initially for application in cancer populations (Portenoy et al., 1994), and subsequently modified after internal consistency testing and validation by an expert panel and people with IBD (Farrell et al., 2015). Data associated with the scale revision determined that, although people with inactive disease appeared to be less affected by symptoms, they encountered up to nine symptoms per week.

This suggests that the physical symptoms of IBD are a constant part of daily life, irrespective of disease stage, with lack of energy being a significant influence on affected individuals.

Table 2.1

Physical symptoms of IBD

Symptom	Crohn's disease	Ulcerative colitis
Diarrhoea	Four or more episodes per day	Four or more episodes per day
Abdominal pain and cramping	Moderate to severe tenderness	Mild tenderness
Blood in stool	Yes	Yes
Fatigue	Result of excessive blood loss, anaemia, and poor nutritional absorption	Result of excessive blood loss and anaemia
Weight Loss	Common due to poor nutritional absorption	Seen in more severe cases

Note. Adapted from “Inflammatory bowel disease part II: Crohn's disease--pathophysiology and conventional and alternative treatment options,” by K Head and J. Jurenka, 2004, *Alternative medicine review*, 9(4), p. 362.

Other reports have suggested that lack of energy or fatigue is a serious problem for people with IBD. Fatigue was reported in 40% (N=1187) (Romberg-Camps et al., 2010) to 50% of people with IBD (N=81) through the administration of two fatigue instruments (Grimstad et al., 2015). The fatigue visual analogue scores instrument (fVAS) measured fatigue based on where participants indicated their severity of fatigue along a 100-mm horizontal line with 0-mm designating ‘*No Fatigue*’ and 100-mm designating “*Fatigue as bad as it can be*’. Fatigue was defined as greater than 50 mm. The Fatigue Severity Scale (FSS) also measured fatigue based on the mean of nine items that are scored on a 1-7 scale. For this scale, a higher number indicates greater fatigue. Compared to healthy aged-matched controls, the level of fatigue experienced by the new IBD patients was significant. Multiple regression analysis of the data also reported that fatigue, as measured by the fVAS and FSS, had an impact on psychological factors such as depression.

Many individuals with bowel disease also report that depression and anxiety are two of their major symptoms. The most common measure of depression and anxiety in people with IBD is HADS (Jordan, Sin, Fear, & Chalder, 2016; Neuendorf, Harding, Stello, Hanes, & Wahbeh, 2016), with 52 of 171 studies that measured depression and anxiety in people with IBD employing HADS (Neuendorf et al., 2016). Grimstad et al. (2015) reported that higher scores on the depression index of HADS were associated with greater fatigue. Therefore, fatigue and depression appear to be related in that people with IBD who experienced greater levels of fatigue may also experience a greater severity of depressive symptoms.

The high prevalence of depression and anxiety in people with IBD has been previously demonstrated. In a study of 116 individuals with Crohn's disease (N=75) and ulcerative colitis (N= 37), IBD had a significant psychological impact as measured by HADS (Guthrie et al., 2002). It was indicated that 47.4% (N=116) of participants scored eight or above on the anxiety scale, the depression scale, or both. This figure is similar to other reports where a score of eight or above was reported in 43% (N=231) (Bennebroek Evertsz et al., 2012) and 44.6% (N=147) of people with IBD (Gómez-Gil et al., 2008). The results of these studies are consistent in that nearly half of the surveyed participants reported either a possible anxiety disorder, depression, or both. A further 25.9% (Guthrie et al., 2002) and 15.8% (Gómez-Gil et al., 2008) scored 11 or above on both or one of the scales, indicating probable clinical depression, anxiety, or both. These results indicate that anxiety and/or depression is a genuine concern for people with IBD. This is confounded when these scores are compared to the general adult population. Anxiety and depression scores recorded in 4,410 adults in the general population indicated that 3.2% scored eight or above on the anxiety scale, depression scale or both (Hinz & Brähler, 2011).

The psychological influence of the disease can have psychosocial consequences for people with IBD. For example, men and women diagnosed with IBD described the impact of their disease on their willingness to participate in social engagements (Matini & Ogden, 2016) or discuss their disease with family and friends (Norton et al., 2012). In video diaries and focus group discussions, 48 participants with IBD explained that family and friends would blame their diet and lifestyle choices as reasons for why they had

developed the disease. The lack of understanding of the aetiology of the disease contributed to these individuals with IBD feeling depressed. The inability to count on family and friends for support also reflected the fact that they were tired of defending their choices to not participate in social activities, such as drinking alcohol or eating certain foods that exacerbated their IBD symptoms. Withdrawal from social engagements also contributed to feeling lonely, depressed, and/or anxious. It appeared that the negative psychological impact of IBD caused many people to withdraw from certain situations only to increase this negativity. Although depression and anxiety were not quantitatively measured, the personal accounts of how people with IBD experienced the psychological impact of their disease by changing their social behaviours, demonstrated some of the relevant psychological and social challenges faced by people with IBD.

In addition to these symptoms, IBD is a risk factor for a range of long-term consequences/comorbidities, such as bone mineral loss and osteoporosis at rates that are comparably higher than age and gender-matched individuals without a diagnosis of IBD (Targownik, Bernstein, & Leslie, 2013). In 388 patients with IBD, osteopenia was measured in 78 participants and osteoporosis in an additional 17 (Wada et al., 2015). A review article exploring osteoporosis in IBD reported between 5-37% of patients with IBD were osteoporotic (Reinshagen, 2008). It has also been reported that 18.5% of IBD patients presented with symptoms of arthritis in the knees and ankles (Yuksel et al., 2011). An additional potential comorbidity included chronic obstructive pulmonary disease (COPD) (Vutcovici et al., 2016) and newer research has suggested people with IBD are at an increased risk of cardiovascular diseases (Singh, Kullo, Pardi, & Loftus Jr, 2015). Clearly, people with IBD experience continual physical and psychological impacts in addition to being at an increased risk of developing subsequent comorbidities.

People with IBD appeared to experience physical and psychological symptoms that affected their daily lives and led to an increased risk of developing subsequent comorbidities, such as osteoporosis. Unfortunately, the most burdensome physical symptom, lack of energy or fatigue, is not known to subside during the inactive stage of the disease and is a persistent influence on the daily functioning of people with IBD.

Furthermore, fatigue has been indicated to contribute to depressive symptoms, which appeared to have psychosocial consequences for people with IBD.

Although bowel cancer and IBD can be treated surgically or through medication, many symptoms of disease, such as those previously described, may remain. However, preliminary evidence suggests exercise may be beneficial in easing many of those symptoms associated with bowel disease such as poor QOL, fatigue and depression (Beck et al., 2013; Bilski et al., 2014; Cheville et al., 2013). People with bowel disease therefore, should be encouraged to engage in physical activity (Lynch, van Roekel, & Vallance, 2016; Perez, 2009; Schmitz et al., 2010). The next section will explore further the benefits of exercise in regards to the physical and psychosocial challenges specific to bowel disease sufferers.

2.3 Exercise and people with bowel disease

This section will describe how exercise may mediate some of the various challenges described so far in this chapter. Specifically, this section will discuss the benefits of exercise for people with bowel disease relating to the two separate areas. The benefits of exercise for people with bowel cancers are discussed first, followed by the benefits of exercise for people with IBD. These discussions will provide a detailed account of how exercise may alleviate many of the challenges faced by individuals with bowel disease.

2.3.1 Exercise and people with bowel cancers

The benefits of exercise for people with bowel cancer have not been extensively studied. It has been suggested that the benefits of exercise for individuals with bowel cancers include improved fitness (Fisher et al., 2016) and health-related QOL outcomes such as lower levels of fatigue and higher social functioning (Husson, Mols, Ezendam, Schep, & van de Poll-Franse, 2015; Van Roekel et al., 2015). In a cross-sectional study of 151 bowel cancer survivors, high levels of light physical activity, defined as light housework or slow walking, are associated with reduced disability, distress, fatigue, and improved health-related QOL, compared to low levels of light physical activity. Higher

levels of moderate to vigorous physical activity are also associated with similar benefits. Moreover, higher levels of activity resulted in greater benefits in all cases other than fatigue was also indicated (Van Roekel et al., 2015). No significant difference was found between fatigue scores for people in the highest and the lowest quartile of light physical activity, which may indicate that those in the highest quartile were possibly overexerting themselves and thereby negating any positive benefits of exercise. Consequently, it appears that there might be an upper threshold where the benefits of exercise for bowel cancer survivors are offset by the continual acute fatigue caused by each exercise bout.

Conversely, a recent review of randomised controlled trials concluded that there was only a trend towards short-term benefits associated with exercise interventions for people with bowel cancer (Cramer, Lauche, Klose, Dobos, & Langhorst, 2014). In the three included studies, measures of QOL and fatigue were not significantly different from the usual care control group. However, due to contamination and poor adherence to one of the exercise interventions, one study included in the review conducted an exploratory ancillary analysis and found significant improvements in the exercise group for QOL and anxiety (Courneya et al., 2003). There was also an observed trend towards improved physical well-being, depression, and satisfaction with life. Therefore, the feasibility of the exercise intervention appeared to influence the findings on the benefits of exercise and definitive conclusions on the advantages of exercise warrants further investigation.

A small feasibility study reported on the benefits of exercise for weight loss, improved energy and gut motility in bowel cancer survivors (Anderson, Caswell, Wells, Steele, & Macaskill, 2010). Eighteen bowel cancer survivors, six to 46-weeks post-operation, participated in a personalised three-month lifestyle programme, which included physical activity tracking via pedometers. At the midpoint, participants had significantly increased their physical activity levels. At the completion of the three-month programme, the physical activity levels were no longer statistically significantly compared to baseline. However, participants lost an average of 1.2 kilograms, significantly decreased their waist circumference from 101.7 (\pm 9.9) cm to 98.2 (\pm 9.3) cm, and showed improved QOL at intervention completion. A single semi-structured interview was conducted with each of the participants at the end of the programme as part of the feasibility outcome. Many participants explained that they would not have

increased their physical activity without the assistance of the programme as their knowledge about the importance of physical activity for survivorship was low. The programme involved regular meetings with counsellors and social support which may have contributed to the positive QOL findings. Additionally, the regular meetings may have contributed to the improvements in weight and waist circumference as the individuals that received regular support may have been more inclined to make better food choices or increase their activity levels. However, as the activity levels were not greater at completion, other unknown factors may have contributed to the decrease in weight and waist circumference. A summary of the evidence outlining the benefits of exercise for people with bowel cancers is available in Table 2.2.

Table 2.2

Benefits of exercise for people with bowel cancer

Study	Year	Study Population	Methodology	Findings
Courneya et al.	2003	69 CRC survivors 33 controls	Prospective RCT. Exercise 3-5 times per week for 20-30 min	Improved cardiovascular fitness associated with improvements in QOL in CRC survivors.
Anderson et al.	2010	18 CRC survivors 6 to 46 weeks post-operation	3-month intervention (LiveWell) feasibility study. QOL, weight, and waist circumference measured monthly.	Significant improvements in QOL (p=0.0002) and decrease in waist circumference (p=0.005).
Jonsson, C.A., Stenberg, A., & Frisman, G.H.	2011	13 CRC survivors 1-week post hospital discharge	Giorgi analysis of 13 semi-structured interviews.	Common themes: lack of control, fear of wound and insecurity according to complications.
Taylor, C., Richardson, A., & Cowley S.	2011	16 CRC participants	Longitudinal grounded theory. 4 semi-structured interviews across 12 months following surgery. 62 total interviews included in analysis.	Common Themes: anxiety regarding recurrence, adoption of new behaviours, heightened monitoring and management of the body.
Husson et al.	2014	1458 CRC survivors > 2 years post diagnosis	Longitudinal study. Time spent in MVPA and HRQoL assessed over three time points, one year apart.	CRC survivors who met PA guidelines reported higher physical, role, cognitive, emotional, social functioning, and global HRQoL compared to CRC survivors who did not meet PA guidelines.
Van Roekel et al.	2015	151 Stage I-III CRC survivors 2- to 10- year post diagnosis.	Cross-sectional study. Time spent in LPA, MVPA (h×wk ⁻¹) and HRQoL assessed via questionnaires.	Self-reported LPA and MVPA were significantly and independently associated with higher physical functioning (p=0.05). LPA was significantly associated with higher role functioning (p=0.01) and lower disability (p=0.02).
Abbreviations: CRC, colorectal cancer; RCT, randomised controlled trial; QOL, quality of life; MVPA, moderate-to-vigorous physical activity; HRQoL, health-related quality of life; LPA, light physical activity				

Other evidence suggests that bowel cancer survivors increased their physical activity levels to support recovery and survivorship. In a qualitative study, open-ended interviews with 13 postoperative bowel cancer patients indicated that they increased their activity levels to control the experience of many physical symptoms during the postoperative period (Jonsson, Stenberg, & Frisman, 2011). Patients described how the inability to control flatulence and defecation following surgery made them feel uncomfortable with and out of control of their bodies. Furthermore, thinking about malignancy and cancer recurrence led many of the patients to experience fear and anxiety. Fear was also experienced when thinking about complications as a result of surgery, which the authors concluded led to physical limitations. However, the investigators did not describe the physical limitations met by the newly treated patients, meaning that no speculation can be made on how and in what way these physical limitations may have challenged these participants. However, Jonsson et al. (2011) described how patients discussed the importance of avoiding complications by claiming responsibility for their personal health through pushing themselves and engaging in regular physical activity. Participating in exercise as a means of accountability was reported in a similar study where 16 bowel cancer patients reported increasing their physical activity levels as a way to claim responsibility for their health and decrease the risk of cancer recurrence (C. Taylor, Richardson, & Cowley, 2010).

Exercise was also reported to reduce the risk of bowel cancer recurrence (Denlinger & Engstrom, 2011). A meta-analysis of seven physical activity and bowel cancer-specific survival studies described how physical activity was positively associated with bowel cancer-specific and overall survival (Des Guetz et al., 2013). Furthermore, the level of physical activity post-diagnosis was associated with greater overall survival suggesting a dose-response relationship. Therefore, people with bowel cancers who regularly participated in exercise activities appeared to be living longer and had better QOL. As such, people with bowel cancers are advised to take part in regular physical activity (Denlinger & Engstrom, 2011; Des Guetz et al., 2013; Lynch et al., 2016; Van Blarigan & Meyerhardt, 2015).

2.3.1.1 Levels of physical activity and exercise in people with bowel cancer

It has been suggested that bowel cancer survivors' levels of physical activity declined compared to pre-diagnostic levels (Lynch, Cerin, Newman, & Owen, 2007). In telephone interviews with 1,996 bowel cancer survivors, 53% met activity guidelines of 150 minutes per week pre-diagnosis compared to 32% following diagnosis, which is consistent with other observations relating to how few bowel cancer survivors meet physical activity guidelines (Spector, 2014). Additionally, people with bowel cancers are 56% more likely to be sedentary than the general public (Hawkes, Lynch, Youlden, Owen, & Aitken, 2008). This is contrary to a larger study that reported 82% of bowel cancers survivors met physical activity guidelines of 150 minutes of moderate-to-vigorous physical activity at 2-5 years and >5 years since diagnosis (Husson et al., 2015). In the longitudinal study, 3,858 bowel cancer survivors were mailed questionnaires assessing their levels of physical activity at three time periods, each one year apart. At times one, two, and three, response rates were 73% (n=2625), 83% (n=1643), and 82% (n=1458) respectively. The high response rate and the number of participants meeting activity guidelines may have been susceptible to survivorship bias because a sedentary lifestyle is related to mortality for bowel cancer survivors; therefore, participants may have inflated their activity levels to appease the researchers and conformed to demand characteristics. Furthermore, inactive participants may have only completed one survey, as the number of participants that reported being inactive the third time was less than those that they were inactive the second time. The relatively stable response rates indicate that some bowel cancer survivors were potentially aware of some of the benefits of exercise and participated in physical activities. While these results show some variation in physical activity patterns in individuals with bowel cancer, an increase in the levels of physical activity for the bowel cancer population would likely lead to a range of positive physical and psychosocial outcomes.

2.3.2 Exercise and people with IBD

Similar to the bowel cancer research, the benefits of exercise for people with IBD have not been extensively examined. The available evidence has been outlined in Table 2.3. Two recent review articles, including one systematic review, have demonstrated that exercise was a safe and beneficial method that could contribute to improving some

symptoms and improving QOL in individuals with IBD (Bilski et al., 2014; Packer, Hoffman-Goetz, & Ward, 2010). The first study in this area was a pilot study that tested the safety and efficacy of a 12-week walking exercise program in 16 sedentary patients with Crohn's disease (Loudon, Corroll, Butcher, Rawsthorne, & Bernstein, 1999). Participants completed measures of physical and psychological factors including stress, QOL, disease activity, body mass index, and cardiovascular function one week prior and immediately following the 12-week intervention period. Two of the 16 participants dropped out of the study due to issues unrelated to their disease, which suggested that the exercise program was safe for people with Crohn's disease. Additionally, psychological factors, such as stress, measured by the IBD Stress Index, and physiological factors, such as aerobic capacity, improved significantly with a trend towards improved body mass index at the end of the 12 week walking program. The physical and psychological improvements suggested the exercise program was also successful in enhancing the lives of people with Crohn's disease. These findings should be interpreted with caution due to the unusually small sample size of 12 participants. However, the purpose of the study was to test the feasibility of an exercise intervention for people with Crohn's disease and was successful in achieving that objective as there was no disease related withdrawals.

Table 2.3

Benefits of exercise for people with IBD

Study	Year	Study Population	Methodology	Findings
Loudon et al.	1999	12 patients with Crohn's disease.	Pilot exercise intervention. Thrice weekly 12-week walking program	Significant improvements in IBD stress Index ($p=0.0005$), IBDQ ($p=0.01$), Harvey and Bradshaw Index ($p=0.02$), VO_{2max} (ml/kg/min) ($p=0.0013$).
Ponich et al.	2003	24 patients with Crohn's disease	RCT. Exercise intervention: thrice weekly 24-week progressive resistance training program.	Significant improvements in SF-36 ($p=0.042$), grip strength ($p=0.038$) and 2MW ($p=0.003$) at 12 weeks in the exercise group compared to controls. No final analysis data available.
Packer et al..	2010	89 patients with IBD and 94 controls	Systematic Review	Low to moderate physical activity is associated with improved IBDQ ($p<0.05$), IBDSI ($p<0.05$). PA has small effect in reducing inflammatory disease burden.
Klare et al.	2015	30 patients with mild-to-moderate IBD	RCT. Exercise intervention: moderate thrice weekly 10 week running program.	Significant improvement in social dimension of IBDQ between exercisers and controls.
Chae et al.	2016	158 IBD patients	Cross-sectional and descriptive analysis	IBD patients reported exercise to be pleasant (57.7%), beneficial (80.5%), sensible (71.8%), uplifting (61%) good (70.5%) and enjoyable (44.4%).

Abbreviations: IBDQ, Inflammatory Bowel Disease Questionnaire; SF-36, Physical and Mental Health Questionnaire; 2MW, 2-minute walk test; IBDSI, Inflammatory Bowel Disease Stress Index.

Subsequent studies have substantiated the benefits reported by Loudon et al. (1999). For instance, a 10-week moderate intensity running programme significantly improved psychological variables in 30 people diagnosed with IBD, with a trend towards improvement in BMI (Klare et al., 2015). The social well-being sub score of QOL improved significantly at the end of the 10-week intervention period in 15 participants with IBD randomised to the exercise intervention group. The control group participants were advised to maintain their current physical activity routines. However, as 20% of the control group participated in weekly exercise sessions of singles tennis, yoga, surfing, or volleyball, their levels of physical activity may have influenced the findings as there were improvements in subscales of QOL measured in the control group over the 10-week intervention period. Additionally, the activity of the control group was not monitored resulting in a crossover effect, whereby controls become more active due to their participation in an exercise study. This may explain why social functioning was the only subscale to yield statistically significant results following the intervention period, as controls exercising outside of the program were not exposed to the social components associated with exercising as part of a group. However, similar to Loudon et al. (1999), the 10-week exercise intervention was completed safely and provided people with IBD improvements in their QOL.

Resistance training has been suggested to decrease the risk of arthritis in IBD patients (Ponich, O'Sullivan, Sparrow, & Walton-Mennill, 2003). Twenty-four patients diagnosed with Crohn's disease were randomised into an exercise group or a control group. At 12 weeks there was a trend towards an increase in bone mineral density and significant improvements in perceived health, grip strength, and two-minute walk test in the exercise group compared to controls. This study was published as an abstract in a journal supplement prior to final analysis; therefore, details surrounding the exercise protocol and the results at 24 weeks are not reported. However, the findings suggest that people with IBD can safely participate in resistance training and that it is a form of exercise that provides many benefits to individuals with IBD.

Additionally, people with IBD appear to enjoy exercising and think positively towards the idea of participating. An analysis of the attitudes of individuals with IBD towards exercise indicated that exercise was enjoyable (44.4%), beneficial (80.5%), and

uplifting (61%) (Chae, Yang, Kim, Park, & Jeon, 2016). Women with IBD reported exercising to help control their disease and some of their symptoms (Sykes, Fletcher, & Schneider, 2015) with higher exercise levels associated with a decrease in developing active IBD (P. D. Jones et al., 2015). In a large cohort study, the physical activity levels of 1,857 individuals with either Crohn's disease or ulcerative colitis were assessed using The Godin Leisure Time Activity Index at baseline and six months. This self-report measures physical activity through the following formula:

$$\text{Weekly leisure activity score} = (9 \times \text{Strenuous}) + (5 \times \text{Moderate}) + (3 \times \text{Light})$$

At six months, 20% of people with Crohn's disease that were in a low exerciser category (Godin Index < 28) experienced a relapse versus 15% of people with Crohn's disease who exercised frequently (Godin Index \geq 28). There was a trend towards this relationship for the participants with ulcerative colitis with 28% of participants in the low exercise category experiencing active disease versus 21% of the frequent exercisers. These relationships are corroborated by indications that participation in exercise or physical activity was associated with a decline in disease activity (Packer et al., 2010).

2.3.2.1 Levels of physical activity and exercise in people with IBD

Research on the prevalence of exercise for people with IBD is limited. An assessment of a self-report leisure time physical activity study indicated that 58% and 53.6% of people with Crohn's disease or ulcerative colitis respectively, were inactive (Mack, Wilson, Gilmore, & Gunnell, 2011). Activity levels were defined based on scores from the Physical Activity Monitor. This is a self-report measure where participants are asked to specify from a list of 21 activities how frequently in the previous three months they engaged in each activity. The self-reported durations are then multiplied by the estimated energy expenditure of each activity expressed as kilocalories expended per kilogram of body weight per hour of activity. The sum was then converted from yearly estimates into daily estimates. Participants expending less than 1.5 kcal/kg/day were classified as being "*inactive*" while "*active*" was expending >3.0 kcals/kg/day. These definitions were based on public health guidelines (Haskell et al., 2007). Further indications suggest people with IBD participated in exercise activities ranging from 20 minutes per week to greater than 80 minutes per week (DeFilippis et al., 2016), up to

about 100 minutes of physical activity a week (Chae et al., 2016). While there are some between-study variations, these studies suggest that many people with IBD are independently insufficiently active to gain health benefits.

In regards to exercise for people with IBD, it seems that although there appears to be evidence supporting exercise for people with IBD, the level of evidence is low. This is due in part to small sample sizes and issues relating to the trustworthiness of the data. Consequently, the benefits of exercise for people with IBD should be explored in future research. However, it has been reported people with IBD participate in exercise activities, suggesting they receive some benefits from doing so.

2.4 Physical activity counselling

As the introduction of the thesis has briefly outlined the manner in which exercise is known to contribute to improvements in physical and psychological symptoms, it appeared necessary to explore the information about exercise that people with IBD are exposed to in the healthcare settings. Following a disease diagnosis, a ‘teachable moment’ occurs which people are receptive to health behaviour advice given by health professionals (Karvinen, Bruner, & Truant, 2015; Xiang, 2016). Furthermore, it has been suggested that early exercise interventions have a positive influence on patients QOL (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Therefore, the challenges faced by individuals with bowel disease following a diagnosis and treatment, and the possible mediating effects of exercise and physical activity, suggest that physical activity counselling should occur in the healthcare setting. The literature surrounding physical activity counselling for individuals with bowel disease is especially sparse; however, people with IBD are frequently followed-up by primary healthcare professionals including GPs. As such, this section discusses the physical activity counselling practices for people with bowel cancer, followed by the counselling practices in primary care.

2.4.1 Physical activity counselling in cancer care

Currently, physical activity counselling practices exclusive to bowel cancer care are unknown. This section will address the physical activity counselling practices across all cancer types to provide a justification for exploring bowel cancer as part of this thesis.

Evidence suggests that exercise discussions are becoming part of usual care for people with cancer. The indication is due in part to a 2004 report that implied that an oncologist's recommendation to exercise increased exercise behaviours of newly diagnosed women being treated for breast cancer (Lee W. Jones, Courneya, Fairey, & Mackey, 2004). In the single-blind randomised controlled trial of 450 breast cancer survivors, women randomised to the exercise recommendation group significantly improved their physical activity levels compared to usual care or recommendation plus referral group. Subsequent studies have examined the physical activity counselling or exercise discussion practices of those working in cancer care. One enquiry suggested that 43% (N=281) of oncologists attempted to recommend exercise to their cancer patients (Lee W. Jones, Courneya, Peddle, & Mackey, 2005). However, only 28% of oncologists actually recommended exercise to their patients. In a survey of 199 oncologists, it was reported that nearly 95.5% of them enquired about the activity levels of their patients with some frequency (Karvinen, DuBose, Carney, & Allison, 2010) though only 19% asked patients about their activity levels at every consultation. Most oncologists (44.2%) enquired about the physical activity levels of their patients on most, but not all visits. However, 64.4% and 66.4% of oncologists provided physical activity counselling to their on- and post-treatment patients respectively. These results are comparable to the physical activity promotion practices of oncology nurses where 74.9% enquired about their patients' activity levels, and 65.7% and 66.9% recommended exercise to patients currently receiving treatment or following treatment, respectively (Karvinen et al., 2012). Another oncology nurse survey reported more than half (N=119) promoted physical activity to their patients pre-, during, and post-treatment (Keogh, Puhlinger, et al., 2017). Additionally, a small survey (N=31) of radiation oncologists and urologists reported that one participant "*always*" gave physical activity advice, 11 "*often*" gave physical activity advice, and 14 "*sometimes*" gave physical activity advice to men with prostate cancer (Spellman, Craike, & Livingston, 2013). Based on these findings, it can be suggested

that people with cancer are likely to receive some physical activity counselling from some members of their care team including oncologists and/or nurses. It is possible that the high number of reported physical activity enquiries by the oncologists and the oncology nurses in some of the studies may have been susceptible to response bias whereby those who regularly engaged their patient in discussions about physical activity were more likely to participate in the study and complete the survey. However, the survey of oncology nurses by Keogh, Puhlinger, et al. (2017) included questions relating to nutrition promotion and smoking cessation to deter from any response bias relating specifically to physical activity. Therefore, it can be speculated that some level of physical activity counselling occurred in cancer care.

Conversely, one study reported more than half of surveyed oncologists and surgeons did not regularly discuss physical activity with breast cancer patients (Daley, Bowden, Rea, Billingham, & Carmicheal, 2008). The response rate of 14.4% (102/710) to the survey suggests that response bias may not have played a role in the number of cancer health professionals engaging their patients in exercise discussions. This large variance in reporting of physical activity counselling may have been influenced by the location, as these studies were conducted in four different countries. With the healthcare system of each country vastly different in regards to universal versus privatised healthcare systems as just one example, several possibilities may explain the range in the reporting of physical activity counselling practices of health professionals in cancer care.

Another potential influence on the physical activity counselling practices in cancer care is the personal activity behaviours of the cancer health professional, which may be likely to influence the frequency of activity counselling (Keogh, Olsen, et al., 2017). The extent to which the activity levels reported to affect physical activity counselling practices “*very much*” was 22.4% and 12.3% by oncologists and oncology nurses, respectively (Karvinen et al., 2010; Karvinen et al., 2012). Fourteen percent of oncologists and 22.8% of oncology nurses indicated that their activity levels had no influence on whether they recommended physical activity or exercise to their patients. Based on the findings of these two studies, it appeared that nurses were less influenced by their personal behaviours than oncologists in regards to the counselling of physical activity to their cancer patients. This might suggest that nurses were more attentive to

patients' needs and developed their counselling practices around what was considered appropriate for their patients. However, further research is needed to explore how current physical activity levels influence professional practice regarding their physical counselling practices in cancer care.

The studies investigating the physical activity counselling practices of health professionals in cancer care targeted those responsible for physical activity counselling of all cancers or prostate cancer specifically. However, bowel cancer survivors indicated that they were less likely to receive a recommendation to exercise compared to other cancer groups, specifically, breast, prostate, cervical, or uterine (Sabatino et al., 2007). In the study of 1,600 cancer survivors, including 149 survivors of bowel cancer, it was reported that bowel cancer survivors were also significantly less likely to receive an exercise recommendation than age-matched controls without cancer. Therefore, an exploration of current physical activity counselling practices for people with bowel cancer appears to be highly necessary.

As previously discussed, physical activity offers many benefits to people with bowel cancer, and it appears that at least some healthcare professionals are aware of the benefits of exercise for people with cancer. The extent of this knowledge by healthcare professionals appears to have improved over the last decade. In 2005, 58% of oncology nurses surveyed (N=221) had little or no familiarity with the benefits of exercise for people with cancer and 18% did not know such evidence existed (Stevinson & Fox, 2005). More recently, oncologists and oncology nurses reported that the benefits of exercise included a reduced risk of cancer recurrence and other chronic diseases as well as improved physical functioning. (Karvinen et al., 2010; Karvinen et al., 2012; Keogh, Puhlinger, et al., 2017; Spellman et al., 2013). Additionally, 710 cancer clinicians were asked to identify the context within which they gave physical activity advice to their patients. Their responses were then coded by the researchers and themes were developed. The themes revealed that physical activity was encouraged to improve physical and functional health, assist with weight management, reduce cancer recurrence, and mortality (Daley et al., 2008). A small study of 119 oncology nurses in Australia and New Zealand demonstrated that 90% of nurses believed exercise could improve QOL (Keogh, Puhlinger, et al., 2017). Exercise also led to improvements in mental health,

activities of daily living, and reducing the risk of other disease as reported by 89%, 89%, and 85% of nurses respectively. It seems various health professionals in cancer care are aware of some of the benefits of exercise (Table 2.2) and are encouraging their patients to participate in physical activities; however, the context within which these discussions occur are still mostly unknown.

Table 2.4

Knowledge about the benefits of exercise for people with cancer

Study	Karvinen, McGourty 2012*	Spellman, Craike 2013*	Karvinen, DuBose 2010*	Daley, Bowden 2008	Keogh, Puhlinger 2017*
#	274	31	199	102	119
Population	Oncology Nurses	Clinicians	Med and Rad Oncologists	Oncologists and Surgeons	Oncology Nurses
Reduce risk of recurrence	3.03(1.28)		2.58(1.37)	open-ended question response	59.7%/26.9%
Reduce risk of other diseases	4.26(0.83)		4.20(0.78)		84.9%/3%
Improve mental health	4.69(0.56)		4.52(0.63)		89.1%/0%
Attenuates physical declines from treatment	4.31(0.81)		4.20(0.85)		
Improve QOL		4.52 (0.51)			89.9%/0%
Help patients cope	4.53(0.63)		4.25(0.76)		
Reduce treatment side-effect		3.5 (1.11)			
Improve weight management				open-ended question response	76.5%/11.8%
Improve activities of daily living	4.50(0.66)		4.33(0.76)	open-ended question response	89.1%/0%
Reduce tumour specific comorbidities					69.7%/16.0%
No benefit					0%/77.3%
Benefits for physical and functional health				open-ended question response	

* - Items rated on a 5-point Likert scale ranging from 1 (not at all) to 5 (very much) Results are reported as MEAN(SD)

♦ - Items rated on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Results are reported as %agree/%disagree. Note: Percentages do not equal 100% due to missing data or missing response.

As physical activity is known to provide many benefits to people with cancer, physical activity counselling should play a role in that care. However, numerous barriers to effectively promote and discuss exercise with patients have been identified. Barriers to physical activity counselling included lack of time, uncertainty of what to recommend, hesitations based on safety, and a perception of a lack of patient interest to receiving physical activity counselling (Karvinen et al., 2010; Karvinen et al., 2012; Spellman et al., 2013; Stevinson & Fox, 2005). Oncologists indicated that lack of time was the primary barrier to recommending physical activity to patients (Karvinen et al., 2010; Spellman et al., 2013), while the primary barrier for oncology nurses was the lack of available resources (Stevinson & Fox, 2005) or the perception that patients were uninterested in receiving a recommendation to exercise (Karvinen et al., 2012). However, two focus group discussions with survivors of various cancers, including survivors of bowel cancer, addressed their need for receiving more information about exercise (James-Martin et al., 2014). In this instance, the needs of people with cancer and the nurses' perceptions of those needs did not fully align. Although these findings are from two separate studies and direct inferences cannot be made, further investigations should explore the perceptions of both the patients and the nurses regarding the potential discussions about exercise that are shared in the clinical setting. This would provide insight into physical activity counselling practices and the potential implications that result from those practices.

2.4.2 Physical activity counselling in primary care

Currently, there is no research exploring the physical activity counselling practices of health professionals working with IBD patients specifically. However, many people with IBD are transitioned into primary care from specialty care following a diagnosis of greater than two years and in a stable condition for at least one year (Raghu Subramanian & Triadafilopoulos, 2016). Furthermore, it is argued that primary care could and should care for people with IBD (Bennett et al., 2015), warranting exploration in the literature about physical activity discussions in primary care.

Physical activity counselling or exercise communication is becoming part of usual healthcare in a wide variety of settings and by an equally wide variety of medical and

allied healthcare professionals, namely GPs and nurses. The number of GPs discussing exercise with at least ten patients per week increased by 9% from 1997 to 2007 (Buffart et al., 2009). In 2010, one in three adults who saw a healthcare professional was advised to begin or maintain physical activity levels, an increase of about 10% from the year 2000 (Barnes & Schoenborn, 2012). Furthermore, GPs felt that discussing exercise or physical activity with their patients was a part of their role (Barrett, Darker, & Hussey, 2013; Buffart et al., 2009; Leemrijse, de Bakker, Ooms, & Veenhof, 2015). Therefore, explorations of the practices of physical activity counselling and exercise discussions between healthcare professionals and patients have occurred and add insight to the specifics of this practice, including potential barriers, frequency, motivators, and determinants of physical activity counselling.

Healthcare professionals have been observed to be more confident in treating or curing illness and disease, but may be less confident in promoting healthy behaviours such as exercise (van Achterberg et al., 2011). A survey of 739 practising family doctors reported greater confidence in giving general exercise advice compared to specific advice, such as the recommended exercise intensity or frequency (Bull, Schipper, Jamrozik, & Blanksby, 1995). This may have been reflected in the advice given, as walking was the most frequently recommended activity by primary healthcare providers (Bull et al., 1995; Douglas, Torrance, van Teijlingen, Meloni, & Kerr, 2006). Similarly, a survey of 757 primary care staff including GPs, health visitors, and practice nurses reported that 62% of GPs, 88% of health visitors, and 90% of practice nurses were “*likely*” or “*very likely*” to recommend moderate exercise to apparently healthy adults, yet 85%-98% identified walking as their primary recommendation (Douglas et al., 2006). GPs also appeared to be unaware of any specific exercise guidelines in regards to recommended frequency, intensity, and duration (Barrett et al., 2013; Douglas et al., 2006) which may have also contributed to a relative lack of confidence in promoting exercise or physical activity. However, studies showing that primary healthcare professionals felt confident in advising their patients to exercise regardless of their knowledge of exercise guidelines contradict this suggestion. This implies that while the dissemination of exercise guidelines to healthcare professionals is important, it does not always affect the healthcare

professionals' physical activity counselling practices or perceived confidence in delivering information.

Other barriers have also been identified in literature reviews related to physical activity counselling, which included lack of time, patient receptiveness, lack of skills, and compensation (Eakin, Smith, & Bauman, 2005). In eight studies, 40.6% to 92.5% of 3,257 surveyed medical practitioners (e.g., GPs, practice nurses, nurse practitioners, internal medicine residents, general internists, family practitioners, internal medicine residents, and family physicians) indicated lack of time was the most common barrier to physical activity counselling. Similarly, a systematic review of 19 studies exploring the primary healthcare professionals' perceptions of physical activity counselling, reported lack of time as the most common barrier to promoting exercise to patients, followed by lack of training or knowledge, lack of success changing patient behaviour, and feelings that physical activity counselling was neither relevant or a priority (Hebert, Caughey, & Shuval, 2012). Other GPs reported that patient comorbidities deterred them from discussing exercise (Leemrijse et al., 2015). GPs were also more often to cite lack of time and poor patient compliance as a barrier to physical activity counselling than nurses (Douglas et al., 2006). In a survey of 757 primary care staff, 30.7% of GPs indicated that they believed patients to be unmotivated to follow physical activity counselling advice versus 13.8% of surveyed nurses. This is similar to another study where poor patient compliance was reported as a barrier by 34% of GPs surveyed about their physical activity counselling practices (Barrett et al., 2013). Nurses, therefore, emerge as being more likely to promote physical activity to their patients because they perceive fewer barriers to doing so and feel their patients will follow their advice. However, because each study developed and implemented their own survey, it is difficult to compare barriers as not all studies would have provided the same list of barriers that the participants could choose in the survey.

Despite such obstacles, physical activity counselling in primary care seems to occur, although the number and frequency of healthcare professionals promoting exercise to adults in primary care varies. As mentioned previously, 85%-98% of 757 surveyed GPs, practice nurses, and health visitors recommended exercise to their patients (Douglas et al., 2006). In a survey of 219 Australian medical students and sports scientists, more

than half of those who responded often discussed physical activity with their patients (Gnanendran, Pyne, Fallon, & Fricker, 2011). In New Zealand, one out of eight people reported receiving physical activity advice from a healthcare professional in primary care (Croteau, Schofield, & McLean, 2006). Demographics on the health professionals in primary care was not published by Croteau et al. (2006), so it cannot be determined if physical activity was recommended by family GPs or primary care nurses. The number of healthcare professionals discussing exercise with their patients may vary because of system specific barriers such as time constraints or personal barriers including uncertainty of what to recommend. Healthcare professionals may also have different motivators that contribute to the variation in the frequency of physical activity counselling that occurs in primary care.

For some healthcare professionals, the motivation to promote physical activity was influenced by their own exercise behaviours. One study indicated that the activity levels of healthcare professionals during their adolescent years ($n=174$) strongly influenced their attitudes towards exercise, with more active healthcare professionals having a more favourable attitude towards exercise counselling than those who were inactive during their childhood years (Gnanendran et al., 2011). Additionally, the authors postulated that those healthcare professionals who reported favourable attitudes towards exercise also engaged in more physical activity per week at the time of the study. This may translate into practice because physically active healthcare professionals had described during a focus group interview how engaging in exercise themselves made them credible sources to patients (Din, Moore, Murphy, Wilkinson, & Williams, 2015). Participants in the study explained how they believed being a credible source could have a positive influence on their patients' motivation to become more physically active. However, it is unknown if that influence also corresponded to the types of activities promoted to patients. This may be highly important as the optimal form of physical activity for patients with bowel disease may depend on a variety of factors, including clinical status of the disease, disease and treatment related side-effects and symptoms, other comorbidities, and current physical activity status. As an example, bowel disease patients who had lost considerable muscle mass and bone mineral density may most benefit from a physical activity programme emphasising resistance and/or balance

training to maintain their muscle mass and reduce their risk of fall-related fractures. However, it is presently unclear whether healthcare professionals who participate in resistance and/or balance training may also encourage these forms of physical activity to their patients.

It can be argued that, due to the lack of knowledge healthcare professionals appear to have regarding exercise recommendations for people without disease, healthcare professionals' knowledge surrounding exercise for people with bowel disease may also be lacking. However, when people presented with health complaints they were more likely to receive a recommendation to exercise (Barnes & Schoenborn, 2012; Barrett et al., 2013; Croteau et al., 2006; Douglas et al., 2006). For example, more GPs than nurses indicated they were more likely to advise patients to exercise if it could improve the patient's condition, while nurses were more likely to discuss exercise with all their patients (Douglas et al., 2006). Similarly, a survey indicated 37% of GPs and 20% of physiotherapists were unlikely to counsel healthy patients and more likely to counsel overweight patients or patients with problems relating to hypertension, high level of cholesterol, or diabetes (Barrett et al., 2013). Moreover, people with symptoms of cardiovascular disease, cancer, or diabetes were more likely to receive physical activity counselling based on data from the United States Department of Health and Human Services National Health Interview Survey (Barnes & Schoenborn, 2012). Furthermore, it was suggested that physical activity advice to people with cancer had increased from 25.5% in 2000 to 35.8% in 2010. Unfortunately, the authors did not differentiate between types of cancer and physical activity counselling. In Australia, a survey of 1,799 members of the Australian Health and Social Sciences panel, which is a randomly selected sample of Australian adults, indicated that people with comorbidities including bowel or other cancers, cardiovascular disease, or diabetes, were more likely to receive a physical activity recommendation (Short et al., 2016). Similar to the findings of (Barnes & Schoenborn, 2012), the authors do not differentiate between types of cancer and activity counselling. However, these findings suggest at least some existing knowledge surrounding exercise for people with disease.

2.5 Qualitative research methods in physical activity counselling research

Previous physical activity counselling research has explored the barriers, motivators, and frequencies with which physical activity counselling occurred (Daley et al., 2008; Karvinen et al., 2010; Karvinen et al., 2012; Stevinson & Fox, 2005). While most of the physical activity counselling research has been quantitative, qualitative methods have explored physical activity counselling. For instance, an open-ended questionnaire assessed the physical activity counselling practices of 102 breast cancer oncologists and surgeons (Daley et al., 2008). The open-ended questionnaires indicated that exercise was promoted or encouraged within five main themes that included; benefits for recurrence and mortality, physical and functional health benefits, healthy active living benefits, and general statements regarding promotion and prescription of physical activity. While these themes are important in understanding some of the physical activity counselling practices of healthcare professionals, questions relating to the context within which and how these discussions were initiated remain unanswered. The context and how physical activity counselling discussions occurred are important features of clinical practice because they provide valuable knowledge about the specifics into patient care.

Semi-structured interviews with healthcare professionals (consultants, nurses, GPs, pharmacists, radiographers, cancer information officers, and screening nurse specialists) who were in direct contact with people with various types of cancer, mentioned exercise as a method for alleviating cancer-related fatigue, which provided some context within which physical activity or exercise was discussed (Miles, Simon, & Wardle, 2010). In this instance, a particular purpose or reason identified why exercise was promoted. The authors concluded that lack of training and knowledge contributed to exercise or physical activity being omitted from discussions about exercise contributing to a decrease in recurrence. One limitation of the study was that the semi-structured interviews included health professionals that cared for a range of cancer patients and was not specified in the investigation. As exercise has not been explicitly established as beneficial across all cancer types, it is possible that the findings underrepresented the physical activity counselling practices for people with bowel cancer. Additionally, the

purpose of Miles et al. (2010)'s study was to explore what information healthcare professionals shared with cancer patients who enquired about the causes of their cancer. Therefore, the findings do not thoroughly describe the practice of physical activity counselling, although a brief explanation mentioned one particular context of exercise promotion.

To date, only one study has explored physical activity counselling from the patients' perspectives. The study explored the health perceptions of people with bowel cancer and indicated that some participants lacked the motivation to change their behaviour because they suspected that they did not need to participate as they were under surveillance of their doctor or other healthcare professionals (Hardcastle et al., 2016). The authors concluded that this belief underscores the importance of physical activity counselling as people with bowel cancer may benefit from such discussions. The semi-structured interviews provided knowledge as to why people with bowel cancer lacked the motivation to change i.e. they felt being under doctor surveillance was enough to keep them healthy. Qualitative methods in physical activity counselling may be able to answer why some of the barriers to behaviour change occur rather than simply identifying their existence.

2.6 Conclusion

This chapter has explored exercise and the physical activity counselling practices in healthcare. It began with a review of the physical and psychosocial challenges people with bowel cancer or IBD encounter, the benefits of exercise to help alleviate some of those challenges, and finally the prevalence of physical activity in these populations. Next, physical activity counselling in healthcare was examined by exploring the physical activity counselling practices in cancer care followed by primary care. A review of physical activity counselling practices of health professionals in cancer care including an analysis of the frequency of counselling practices, followed by an examination of the barriers, motivators, and determinants experienced by these healthcare professionals was discussed. According to the literature, physical activity counselling practices with people with IBD has yet to be explored. However, as many individuals with IBD are followed

up by primary care, the physical activity counselling practices in this population was examined to provide insight into how and within what context these discussions may occur. The frequency of physical activity promotion in primary care was followed by an examination of the barriers, determinants, and motivators that healthcare professionals encounter as part of their physical activity counselling practice. The literature demonstrates that in spite of numerous exercise counselling barriers, many healthcare professionals are encouraging physical activity among their patients.

This chapter identified several physical and psychosocial challenges people with bowel disease experience. It has also become apparent that although many of these challenges continue to affect the lives of individuals diagnosed with bowel disease, physical activity and exercise have been shown to provide relief and ease many of the persistent symptoms of bowel disease including fatigue and depression. However, the review of the bowel disease and exercise literature identifies a need for further investigations into the effect of exercise for people with bowel disease. While there is some evidence to suggest that people with bowel disease benefit from engaging in exercise and physical activity, further information is needed in regards to how those with bowel disease engage in communication about exercise. Exploring how people with bowel disease discuss exercise among themselves and with their healthcare professionals can advance the understanding of the effects of exercise on the experience of living with bowel disease. Through learning about how people with bowel disease share information about exercise with others, an understanding of the issues relating to exercise specific to those with bowel disease can be recognised.

Reviewing this literature also identifies a clear gap in the literature around physical activity counselling for people with bowel disease. While there are currently exercise guidelines for people with bowel disease, this section highlighted that no information is currently available on how these guidelines were encouraged or discussed in bowel disease care. Additionally, if healthcare providers are unsure of exercise guidelines for their patients, yet are confident in promoting physical activity and exercise to them, it is unclear whether the information being promoted to patients is evidence-based in regards to the likely benefits and risks. Furthermore, questions arise as to the association between knowledge of guidelines and confidence in promoting physical

activity to their patients. This is important as there is the potential that physical activity or exercise performed incorrectly and without guidance, especially for people with diseases, may lead to injuries and other adverse consequences including the exacerbation rather than a reduction in bowel disease symptoms.

Barriers to physical activity counselling in primary care have been recognised and further research can begin to explore how to overcome these barriers. In the bowel disease literature, there is limited information regarding physical activity counselling. This lack of evidence makes it difficult for healthcare professionals to apply an evidence-based approach to improve their physical activity counselling skills and processes for people with bowel disease. By exploring physical activity counselling and exercise discussions for people with bowel disease, further research can address any discrepancies and inefficiencies of the findings.

A review of the literature has indicated that the physical activity counselling practices of people who care for bowel disease patients have also been mostly quantitative. Such methods have provided a brief overview of the barriers, motivators, and facilitators of physical activity counselling, and pose strengths in the provision of information relating to the frequency of physical activity counselling. However, the specifics of individual practice, such as details surrounding the context of such discussions and how discussions about exercise or physical activity were initiated, are important questions relating to the practice of exercise discussions in the healthcare setting. Daley et al. (2008) provided an opportunity for cancer health professionals to give insight into the context of physical activity counselling through a qualitative approach, yet open-ended survey questions are only able to partially answer this question. The context of every clinical discussion about exercise is likely to be different and how healthcare professionals adapt to these differing circumstances can answer important questions about the practice of physical activity counselling, such as the role of these discussions in the patient's ongoing care. Therefore, to appreciate the context within which physical activity counselling occurs in the healthcare setting, qualitative methods should be employed. The next chapter will describe the theoretical, methodological and analytical frameworks of the qualitative approach used in this thesis. Chapter Three will

also explore the analytic process utilised across this thesis and discuss the quality of this thesis as defined by the validity and reliability of qualitative research.

Chapter 3

Exploring experiences: methodological and theoretical frameworks

3.1 Introduction

Chapters One and Two reviewed the literature surrounding exercise for people with bowel disease paying particular attention to the physical activity counselling discussions within bowel disease care. Chapter One identified the aim of this thesis, which is to explore how and within what context exercise is discussed with people with bowel disease. Three distinct studies will examine this objective. The first study is an analysis of commentary exchanged in an online, public, bowel cancer forum, which will capture the patients' perspectives of the effects of exercise on the experience of living with bowel disease. The second study is a semi-structured interview design, which explores the perceptions of people with bowel disease regarding the physical activity counselling they have received from the healthcare professionals who cared for them. The final study also deploys semi-structured interviews with nurses, and seeks to understand their perceptions regarding their physical activity counselling practices for their bowel disease patients through an analysis of their experiences.

To appreciate why physical activity counselling requires a qualitative exploration through nurses' and patients' experiences, and to understand how to obtain insight into the experience of nurses and patients, it is important to describe the theoretical frameworks and methods that were chosen to guide this thesis. This chapter will discuss qualitative research as the methodological framework, alongside phenomenology and symbolic interactionism as the theoretical frameworks that guided this research. The research framework of this thesis will be explored first through a commentary of qualitative health research. Next, the chosen theoretical frameworks that guided the qualitative enquiry will be discussed. Finally, this chapter describes reflexivity, as this relates to the reliability and validity of qualitative research.

3.2 Research framework

3.2.1 Qualitative health research

Denzin and Lincoln (2011) offer a broad definition of qualitative research. They argue:

“Qualitative research is a situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.”
(pg.3)

From the definition offered above, it is understood that qualitative research is a methodology that embraces the many ways in which the world is interpreted through understanding how people ascribe meanings to them. This type of enquiry focuses on the authenticity with which people navigate themselves within their worlds through visual representations or the written and spoken word. Most importantly, it accepts the ontological views of the participants of the research (Rice & Ezzy, 1999). In this way, qualitative research brings the personal experiences into the scientific world.

Qualitative health research explores the social contexts of health and the experience of illness (Gelling, 2015; Morse, 2012a). Collecting and analysing information from the written or spoken word develops an understanding of how illness and disease affect those who experience it. This methodological paradigm often explores a particular experience relating to illness and disease that cannot be obtained quantitatively (Morse, 2011). It is a field of enquiry invested in the human experience of disease and is separate from the biomedical field of medicine. It seeks to examine illness and disease from a holistic view by accepting and acknowledging that the experience of the participant is part of the disease and not separate from it (Rice & Ezzy, 1999). In this way, qualitative health research helps bring the human experience into medicine.

Qualitative health research is separate from general qualitative enquiry in that it may require method modifications to protect or ease any burden that may be placed on participants of qualitative health research (Morse, 2010, 2012b). As opposed to general qualitative enquiry, qualitative health research can be quite distressing for some participants (Richards & Schwartz, 2002). Therefore, data collection may be cut short or collected in small increments. Additionally, the method of data collection may be modified to serve what is best for the participant, and not necessarily what is best for the research question (Morse, 2010).

Furthermore, specific to qualitative health research, qualitative health researchers are likely to encounter certain boundaries as a result of the investigation. It is argued that the boundaries surrounding the researcher and participant relationship can become “blurry” as a result of qualitative health research (Dickson-Swift, James, Kippen, & Liamputtong, 2006). As the nature of qualitative health research relies on rapport and trust between researcher and participant to facilitate an open exchange of information, researchers revealed that many times this encouraged a shift from a professional relationship into a friendship, or a relationship between a counsellor and a patient. These relationship changes may have ethical implications as the researcher may be ill-equipped in how to assist participants in receiving the proper care and treatment they may need, which may result in unnecessary harm placed on the participant as a consequence of the investigation. As minimising harm is a fundamental principal in qualitative research ethics (Traianou, 2014), special consideration to relationships developed within a research context should be made.

Morse (2012b) defined qualitative health research as “a research approach exploring health and illness as they are perceived by the people themselves, rather than from the researcher’s perspective.” (pg. 21). She argued that qualitative health research was able to explore the gaps in quantitative investigations by blending the why, how, and what of issues relating to health. One area in which qualitative research helps fill the gaps is in exploring the experiences and practices of health care, including health communication

3.2.2 Qualitative research in health communication

Health communication occurs on many levels and involves the sharing of information about health between individuals, groups, and systems. This field of enquiry answers questions regarding the effectiveness of communication, consumer awareness of health communication, and health counselling by healthcare professionals (Aarva, de Haes, & Visser, 1997). Furthermore, qualitative health research takes a relativist stance by providing each perspective with the same consideration (Britten, 2011). This neutrality is important when exploring the experience of physical activity communication in the medical setting. Discussions within this setting may be susceptible to one-sidedness, where the nurse is believed to be more informed than the patient in regards to how people with bowel disease overcome potential obstacles, including information about maintaining a physically active lifestyle. Similar occurrences may transpire between people with bowel disease where those that found it easy to exercise may not understand the struggles others experience when trying to exercise. This may become a point of conflict among the two parties. When exploring health communication qualitatively, questions such as the effect of one-sided conversations on the patients' self-confidence to engage in physical activity can potentially address uncertainties surrounding these circumstances. Therefore, health communication between individuals, such as between patients and patients with nurses, as explored in this thesis, requires a close examination of the importance of qualitative methods. Qualitative methods are necessary to answer questions about 'how' and 'why' of a particular phenomenon. Exploring 'how' health communication is practised is central to providing frameworks and guidance on creating best practices. Exploring 'why' health communication occurs answers important questions regarding the motivators and determinants of practice.

3.2.3 The Internet and qualitative research methods

Qualitative research methods that can be applied through the Internet or online include online interviews, online focus groups, and online observation (Mann & Stewart, 2000). These methods differ from traditional qualitative research methods in the collection of data as it can be collected either synchronously, occurring in real time, or asynchronously which allows people to respond in their own time (Jowett, Peel, & Shaw, 2011; Meho, 2006; Redlich-Amirav & Higginbottom, 2014). Applying online research

methods requires careful consideration of the research question in conjunction with issues related to practicality and the methodological and theoretical underpinnings (Bjerke, 2010). For example, if non-verbal cues are important facets to the research question, an online platform will not provide that information and is, therefore, inappropriate (Redlich-Amirav & Higginbottom, 2014). However, using the Internet to collect data reduces any interviewer/interviewee effect that might influence telephone or face-to-face data collection (Meho, 2006) such as the potential for the participant choosing not to disclose intimate or potentially embarrassing topics for fear of judgement by an interviewer.

The Internet is used to collect qualitative data because it can connect people from geographically distant locations by alleviating difficulties associated with time and place coordination, and facilitate complete anonymity for the participant (Cook, 2012). For example, email interviewing was the preferred method to explore young Asian American's experiences of immigrating to the United States of America and their experiences adapting to their new life (Kim, Brenner, Liang, & Asay, 2003). Traditional Asian cultures typically value strong family ties and sharing negative stories about parents and elders would be considered shameful by the community, so online interviews provided a safe space to share experiences. Findings reported by Kim et al. (2003) were similar to studies using traditional face-to-face methods in identifying Asian American's sense of connectedness to their home country and emotional stress. Similarly, the effects of stress on functional impairments associated with Asperger's syndrome was explored using Internet instant messaging because it was considered more comfortable for the participants as it allowed them to participate from their home (R. S. Smith & Sharp, 2013). These results reported did not differ from their similar studies using traditional face-to-face methods in identifying sensory events, emotional functioning and certain behavioural nuances of people with Asperger's syndrome. Therefore, online interviewing is a viable source for qualitative data collection.

The Internet is also used to conduct and collect information using online focus groups. Harmsen et al. (2013) utilised online focus groups to explore why some parents refuse childhood vaccinations. The authors chose the online method because people who shared the decision not to vaccinate their children were geographically dispersed and

face-to-face focus groups were not feasible. Additionally, time constraints allowed participants to post to the online discussion at a time convenient for them.

Data collected in online focus groups is also similar when comparing face-to-face and online focus groups discussions, as observed by an investigation of recreational activities at a Naval Training Centre in online focus groups and face-to-face focus groups (Underhill & Olmsted, 2003). The analysis reported no significant differences between these modes of data collection on the participation rates, the number of unique ideas and relevant comments generated, participant satisfaction, or level of perceived social presence. Unfortunately, the theme names were not reported so the question of whether similar themes were produced remains unanswered. However, the similarities in the number of unique ideas suggests qualitative data collected in online focus groups is comparable to face-to-face focus groups regarding the generation of themes.

In summary, the Internet is becoming more widely accepted as a tool to conduct qualitative research. Current research supports using the Internet to collect qualitative data because it provides many of the same results as the traditional face-to-face methods, can maintain the complete anonymity of the participant, collect rich data from geographically dispersed participants, and can observe linguistic interactions in a naturalistic setting (Hewson, 2014). Qualitative research methods utilising the Internet can also understand the ways social norms are constructed, understood, and reproduced (Markham, 2004). Qualitative research methods using the Internet, specifically observation of online discussions, has also created a new way to observe human contact and behaviour (Markham, 2004; Sade-Beck, 2004) and is one way to explore the lived experience (Hooley, Wellens, & Marriott, 2012).

3.2.3.1 Online observations

The Internet has created a new source from which data can be extracted. This applies in particular to online observations. The easily searchable archived data available online can provide qualitative health researchers with invaluable data in regards to how people with chronic diseases live with disease. By searching through discussion forums and publicly available online support groups, a wealth of information can contribute to advancing the knowledge of the experiences of living with disease. Online observations

of public discussion forums provide researchers with an authentic view of how people with disease conduct themselves in relation to others. This method is similar to traditional observation in that the researcher maintains an outsider perspective with a view into how a participant behaves in a particular context.

Online observations can be conducted by accessing asynchronous archived discussions, observing asynchronous discussions in ‘real time’, or observing synchronous discussions (Hewson, 2014). Asynchronous online observation of computer-mediated communication allows researchers to follow linguistic exchanges discreetly in a “naturalistic setting” (Bordia, 1996). For example, accessing archived conversations on health message boards allowed Macias, Lewis, and Smith (2005) to explore the type of information participants shared in regards to medicines and medical treatments or procedures. However, online observations of archived discussions do not allow for researcher participation nor do they necessarily favour participant consent (Hewson, 2014), as tracking and contacting members who posted online sometimes many years ago is challenging and sometimes nearly impossible.

Real time observations of online discussions allow researchers to participate in the online discussion. Observing asynchronous discussions in real-time involves the researcher joining an online discussion group and then witnessing conversations as they unfold (Hewson, 2014). A real-time asynchronous discussion is where messages are exchanged over a designated time frame, usually assigned by the researcher, that involves a period of weeks or months. The messages do not necessarily need to be continuously exchanged as seen in a chat room. This method was used to observe members of a pro-anorexia discussion board (N. J. Fox, Ward, & O'Rourke, 2005). The researcher disclosed their identity, asked members of the discussion board questions, and conducted private conversations with members who chose to contact him directly. One benefit of real-time observation is researcher participation because the researcher can actively probe members for further information, although such direct contact with the participants may limit the number of participants in such studies.

The final method of online observation discussed here is observing synchronous discussions. This involves researcher disclosed or undisclosed observation of real-time

conversations occurring in live chat rooms (Hewson, 2014). Rodino (1997) silently observed a real-time online conversation on a public Internet chat channel and qualitatively analysed gender constructs based on the lines of text generated over a 40-minute period. Unlike the other two methods previously discussed, participants involved in the chat room discussion have much less time to carefully construct their responses, so a more natural online conversation is conducted.

Clearly, the analysis of online observations provides a unique perspective from which to view the experience of a particular phenomenon, including disease. However, this method provides only a synopsis of that experience, as the ability to probe for further information is limited. To account for this weakness, this thesis also utilised face to face and telephone semi-structured interviews to engage participants in sharing their experience of disease (Chapter Five) and physical activity counselling (Chapter Five and Six).

3.2.3.2 Semi-Structured in-depth interviewing

As the literature demonstrated that physical activity counselling in bowel disease was not well known, this thesis required another qualitative method that would be flexible in its capacity to gather data on different experiences. It also needed the ability to account for the fact that each experience may be different and that each nurse participant or individual with bowel disease may or may not have engaged in a discussion about physical activity. Following a review of qualitative research methods, semi-structured interviews were chosen as the data collection method for Chapters Five and Six.

Semi-structured interviews are conversations with a purpose and are commonly used in qualitative health research (Hansen, 2006). They encase an understanding of the world through communication (Leavy, 2014), by providing the researcher with an opportunity to understand how people perceive their own actions and experiences, and the meanings they assign to them (Hansen, 2006). The dialogue between interviewer and interviewee follows a certain conversational flow. Brinkmann (2014) argued that that exchange begins with a question followed by a negotiation of the meaning of the question. A description is given next by the interviewee. The interviewer then provides an

interpretation of this description, followed by either a validation or clarification by the interviewee. The validation or clarification usually ends the sequence which begins again with a new question. However, the authors argue that should the description require further explanation, the interviewer can pose further questions about the description.

During this exchange, the interviewer follows a flexible interview guide or schedule (Gratton & Jones, 2010). The interview schedule is not designed to be followed precisely, but rather as a resource the interviewer may refer to, as a reminder of the topics to raise during the interview. The unconfined structure of the interview guide is necessary as there are many unknowns regarding physical activity counselling for individuals with bowel disease. This method allows the researcher to probe for further information regarding participants' experiences if more information was needed to understand that experience. Therefore, a semi-structured approach addresses the major issues relevant to this thesis, such as the context within which people affected by bowel disease discussed physical activity.

The next step in developing the research methodology was selecting the appropriate theories that would guide this enquiry. Theory, in qualitative health research, contributes to the critical appraisal of phenomena (M. Kelly, 2010). With the research objectives in mind, specifically how and in what context people with bowel disease discussed physical activity, the theoretical frameworks that were chosen assist in answering the research aim. In this thesis, symbolic interactionism and phenomenology were selected as the theoretical foundations that guided this qualitative enquiry. These theoretical frameworks are discussed in the next section.

3.3 Theoretical approaches

3.3.1 Symbolic interactionism

Symbolic interactionism is a conceptual framework developed by George Herbert Mead (1863-1931) and Herbert Blumer (1900-1987) and asserts that human beings respond to situations and experiences based on the meanings they have given to those situations or experiences (Flick, 2009). This theory poses that reality is based upon interactions between others and is built on social as well as personal understandings. Instead of responding to the actions of others, human beings respond to the meanings and

interpretations of the action that another person exerts (Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2015). This is especially relevant when investigating how people communicate with each other, as often a response is initiated based on the context and the interpretation of the topic of the discussion.

People form meanings as a result of their own experiences (Aksan, Kisac, Aydin, & Demirbiken, 2009) and as a result, the meanings should be regarded in the context of their environment (Benzies & Allen, 2001). In this way, individuals become a product of the meanings and symbols they create and form as a result of their experiences of their world. Therefore, people cannot be viewed solely as an individual, but as an individual within a social context (Spencer, Pryce, & Walsh, 2014). This is particularly important in exploring the experiences of bowel disease and interactions with healthcare providers, as these experiences will continually change as a result of a change in the severity of disease and the continual monitoring by healthcare professionals.

The theoretical framework of symbolic interactionism makes three critical assumptions (Spencer et al., 2014). First, the meanings people have towards things determine the ways in which they act towards it. Second, social interaction with others determines the meanings of such things, and thirdly, the meanings of things are modified through reflection and interpretation when interacting with the thing. This process is continuous as the meanings always change because the interactions and presentations are always different. Therefore, the meanings or symbols that people associate with certain experiences or meanings in their lives are changing in continuous cyclical phases where the previous meanings and experiences will influence future meanings and experiences. Thus, people are always changing and re-evaluating the meanings they associate with their experiences.

As a result of these assumptions, symbolic interactionism provides a robust framework for which to view health and disease. Using symbolic interactionism to guide qualitative health research recognises that the perception of health and disease varies across and within individuals. For example, it is assumed a person's perception of their own personal health will change throughout their experience with IBD. How they define disease for themselves may potentially differ depending on whether they are going

through a period of relapse or a period of remission. This may ultimately affect their willingness to engage in physical activities. Similarly, a person with bowel cancer will mould their perceptions of their own personal health as they transition from diagnosis through to treatment and recovery or survivorship and become comfortable with reengaging in exercise. Furthermore, perceptions of disease prior to disease onset will be influenced by the diagnostic experience and through their first experiences of living with a disease. Therefore, symbolic interactionism is an ideal lens with which to view the experience of living with a disease as these concepts continue to change as more experiences unfold.

3.3.2 Phenomenology

Phenomenology is a theoretical enquiry that originated as a new way of thinking about existence, consciousness and being. The phenomenological approach embraces the idea of understanding an experience as experienced by another (Rice & Ezzy, 1999). It creates a foundation on which to explore how others experience certain events within their own life-world by understanding how and why they perceive phenomena in the way they have described it (Allsop, 2013). Phenomenology strives to explain phenomena by understanding the phenomena from within (Moran, 1999). The objective is to understand people's actions in reference to their intentions and understandings of the action (Carpenter, 2016). This theoretical framework is used heavily in qualitative research aimed at understanding the experiences of participants (Worster & Holmes, 2008).

Two enquiries guide phenomenological research; descriptive and interpretive. Descriptive phenomenology was introduced by Edmund Husserl (1859-1938) and defined as the way that knowledge comes into being (Adams & van Manen, 2008). The word "transcendental" defines this phenomenological philosophy (B. Taylor & Francis, 2013) because it explores where knowing came from and the conditions which make knowing possible. This theoretical approach assumes that an act cannot be complete without understanding all the actions that accompany it (Moran, 2012). Conversely, interpretive phenomenology, introduced by Martin Heidegger (1889-1976) encompasses a phenomenological theoretical approach as finding meaning from being (Carpenter, 2013) and the understanding of being is manifested in the way we act (Cerbone, 2006).

In regards exercise and physical activity, the level with which people with bowel disease participate in such activities will demonstrate the significance of exercise for them in how they choose to live their lives. Additionally, the experience of participating in exercise will likely influence the contexts within which they discuss exercise with each other and their healthcare professionals.

3.3.3 Phenomenology and symbolic interactionism in bowel disease research

Phenomenology and symbolic interactionism have contributed to understanding the experience of bowel disease. For example, symbolic interactionism guided an enquiry into healthcare professional perceptions of cancer cachexia and the needs of those individuals who suffer from the condition (Millar, Reid, & Porter, 2013). This theoretical framework was chosen to explore the healthcare professionals meaning of cachexia and how this meaning influenced their practice because it provided a framework that could investigate how healthcare professionals formed their meaning of cachexia. The study reported that the stage of disease affected the level of cachexia care and management and that uncertainty regarding the hallmark signs of cachexia led to confusion about how to manage the condition. This uncertainty led to people with cachexia experiencing a poor quality of care and highlighted that a lack of clear understanding of disease translates into reduced quality of patient care. While this may seem obvious, several influences can contribute to clearly understanding a disease. These include education, experience, mentorship, research and the implementation of guidelines that provide clear and universal definitions. In a similar study, symbolic interactionism lent theoretical support to semi-structured interviews with people diagnosed with bowel cancer to understand what the main symptoms were that led them to consult a doctor (Ramos et al., 2010). Symbolic interactionism was the chosen theoretical foundation because of the foundational assumptions associated with this theory; behaviour is influenced by the meaning of an experience. Symbolic interactionism can guide inquests into definition standardisation by exploring meanings, shared experiences and an understanding of the nature of the empirical world by the individuals that live it (Pihl-Lesnovska, Hjortswang, Ek, & Frisman, 2010).

Phenomenology guided an enquiry into the nuances associated with being a caregiver for someone with bowel cancer communicating with doctors (McWilliam, Brown, & Stewart, 2000), how healthcare providers perceive levels of fatigue in their patients with IBD (Czuber-Dochan et al., 2014), and to understand end-of-life cancer care from the patient, nurse, family, oncologists. and palliative and critical care consultant's perspectives (Pattison, Carr, Turnock, & Dolan, 2013). Phenomenology was the chosen theoretical framework of these selected studies because it was expected that nurses could apply the information reported to develop specialist knowledge and improve the end-of-life care for their cancer patients by understanding the experiences of others involved in the phenomenon. Similarly, phenomenology is used to collect information about personal experiences that can be utilised to teach others about disease experience and lead to greater empathy in disease management. For instance, phenomenology was used to identify commonalities in the ways people with IBD managed their disease to help clinicians inform future IBD sufferers about disease management (Sykes et al., 2015).

Phenomenology and symbolic interactionism are two theoretical foundations that guide analysis of the lived experience and the development and understanding of meaning. These methodologies complement each other because to understand an experience one must first explore the meanings attributed to that experience. Conducting the research programme to formulate this thesis under both these theoretical frameworks accepts that the participants of this thesis made sense of their experiences by the definitions and meanings they had toward the phenomenon. The theoretical underpinnings worked together to explain the experience of- and discussions relating to- exercise as perceived by people with bowel disease and bowel disease care nurses.

3.4 Inductive thematic analysis

Methods were compared and considered in relation to Thomas (2006), who provided a detailed discussion of the advantages and disadvantages of a variety of qualitative approaches that could be used in health research. The content provided by Thomas (2006), assisted with the selection of an appropriate qualitative method for the thesis. Inductive thematic analysis was deployed as it minimises the risk of data reduction

through extract selection bias, a deficiency which has been associated with other analytic strategies, such as content analysis (Schreier, 2012). As this thesis is exploratory, an inductive thematic analysis (ITA) as described by Braun and Clarke (2006) was undertaken across all studies. This 6-step analytic process looks laterally across a data set to identify and analyse patterns. Table 3.1 outlines and describes the thematic analysis process. Although originally designed for application in psychology, ITA can contribute to health communication research as it does not require specialised training or specific theoretical knowledge, yet provides a conceptual framework on which to build themes.

Table 3.1

Inductive Thematic Analysis Process

Phase	Description of process
Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Searching for themes:	Collating codes into potential theme, gathering all data relevant to potential theme.
Reviewing themes:	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic ‘map’ of the analysis.

Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis to the research question and literature, producing a scholarly report of the analysis.

Note. From "Using thematic analysis in psychology," by V. Braun and V. Clarke, 2006, *Qualitative Research in Psychology*, 3(2), p. 87.

As the analytic process was similar across the three studies of this research programme, the data from Chapter Four will be used to demonstrate the ITA process. The first step of thematic analysis involved familiarisation with the data and entailed reading the data several times. During this process, it was important to make notes about what was in the data. There is no formula for note generation, but reference to any patterns that appeared, or information relevant to the research question were recorded. This included information within the data that made any reference to physical activity or exercise, such as the reference to any benefits, barriers, or the exchange of exercise related information between or among any individuals (Table 3.2).

Table 3.2

Example of initial notes made from data extracts

Data extract	Initial notes
<i>I liked to exercise (walking, yoga) during chemo when I felt up to it (usually in the second week). Helped my sanity and I'm sure also good for my health.</i>	<i>sanity</i>
<i>Walk as much as you can - walking will help the healing process.</i>	<i>healing process</i>

These notes contribute to the development of the initial codes, and is the next step of the analytic process. Initial code generation involved sorting the notes based on the similarities of the notes. Initial notes that described similar nuances within the data set were grouped together and formed the initial codes (Table 3.3). This was completed in a systematic fashion across the data set as a means of maintaining consistency.

Table 3.3

Example of initial code development

Initial note	Initial code
<i>sanity</i>	<i>Spiritual benefits</i>
<i>reconnecting with life</i>	
<i>inner calm</i>	
<i>healing process</i>	<i>Physical benefits</i>
<i>manage side effects</i>	
<i>the best medicine</i>	
<i>complimentary treatment</i>	<i>Medical benefits</i>
<i>holistic approach</i>	

Searching for themes is the third step and involved grouping similar codes together. Themes were developed in the same systematic fashion as the codes, meaning codes that detailed similar nuances were grouped together. This step involved gathering all the data relevant to that theme. Next, the themes were reviewed to ensure they encompassed the complete data set (i.e., all the transcripts, and the coded phrases or extracts from the data set). This step worked as a way of double checking the analysis to ensure the themes embraced the entire data set and not just one part of the transcripts. Theme names were developed next. This process involved creating theme titles that provided a clear and concise explanation of what comprised the theme. The title of the theme had to contribute to the story of the data set as well (Table 3.4).

Table 3.4

Example of final theme development

Initial code	Provisional theme	Final theme
<i>Spiritual benefits</i>		
<i>Physical benefits</i>	<i>Exercise provides holistic benefits</i>	<i>Cultural value of exercise</i>
<i>Medical benefits</i>		

The final step of the analysis of this thesis as outlined by Braun and Clarke (2006) was the scholarly write-up of the analysis. This was achieved through selecting relevant extracts and relating them back to the research question and the literature. The final step of thematic analysis is telling the story using the themes and data extracts to elaborate and provide substance to that story.

ITA is a descriptive method for analysing qualitative data (Howitt, 2010). The author argues that it is descriptive because it examines what was said rather than how it was said. For example, an ITA of semi-structured interviews with one group of bowel disease (specifically bowel cancer) caregivers, identified a need to give further social support to the caregivers (Houldin, 2007). The analysis of those experiencing the caregiving provided relevant and practical information about how to provide better care to the bowel cancer patient through better care and support of the caregiver. Another study conducted an ITA of interviews with oncology nurses about the experience of discussing prognosis-related information with people with advanced cancer (McLennon et al., 2013). The analysis of those interviews highlighted the nurses' position in improving the quality of the prognosis-related communication by being involved in the discussions. These two studies emphasise that ITA can synthesise the personal experiences of several participants into a description of a particular phenomenon.

This thesis adopted two related, yet different, theoretical underpinnings and applied the same analytic method across the three studies of this thesis. The findings from each study formed the foundation on which the next study was developed and assisted in creating the overall story of this thesis. This thesis explored how and the context within which people with bowel disease discuss physical activity by investigating the experience of engaging in physical activity behaviours and the practices and discourses of physical activity counselling. ITA captured important details from within

the data that related to the aim of this thesis. An ITA allowed the researcher to understand the meanings participants gave to both the discussions they had with one another, as well as the meanings they gave to exercise and physical activity through an analysis of their experiences.

3.5 Validity and reliability

Within qualitative health research, trustworthiness is the qualitative equivalent of the positivist term, validity. Validity is defined by Howitt (2010) as ‘the extent that something measures what it is intended to measure.’ (pg. 367) and reliability refers to the ability of other researchers to replicate consistent findings (Hansen, 2006). Together, these two concepts provide a source of measure with which the quality of qualitative research can be determined. Several processes as described by Patton (1999) were taken to ensure the validity and reliability of the data analysed in this thesis. First, a reflexive journal was kept where the researcher made notes of any possible influences caused by personal biases. This is discussed in further detail in the next section. Secondly, method triangulation was conducted as part of this thesis. This involved using different methods to explore similar research aims. Third, this thesis examined the research aims from bowel disease patients and nurses that work with people with bowel disease, contributing to triangulation of sources. Finally, analyst triangulation was conducted. This involved another individual, the principal supervisor of the thesis student, to review and then discuss the data set and theme development. Combining these four processes contributed to the trustworthiness of the findings.

3.5.1 Reflexivity

Reflexivity is the process whereby the researcher openly acknowledges any personal biases and limitations in the research to the reader (G. Russell & Kelly, 2002). Reflexivity is necessary to the qualitative research process as this is where links are made between the literature, theory and methodology (Watt, 2007). This process involves writing in a research journal during the investigation process. This journal provided an outlet for internal discussions to occur, addressing feelings towards any process of the enquiry to be referred to later as part of writing the final analysis. The reflexive journal

encouraged a continuous engagement with the data and research process that assisted with developing meaning from the process. It provided a framework for engaging with the data on a different level and a space to write out any frustrations, revelations or questions about the data or the process as a whole. Each study Chapter (Four, Five and Six) will provide a reflexivity section where any biases towards the data and the analytic process will be discussed. This will also add to the reliability and validity of this thesis as any biases are addressed and reviewed.

3.6 Conclusion

This thesis explores physical activity counselling through qualitative methods guided by a symbolic interactionist and phenomenological approach. Chapter Four explores physical activity counselling through a symbolic interactionist approach. The chapter provides an understanding of how the meaning of physical activity and exercise was formed by people with bowel cancers by analysing their online interactions. Chapter Four also creates some perspective on how people with bowel disease might experience physical activity counselling. Chapters Five and Six explore further how and the context with which physical activity counselling occurred by taking a phenomenological approach through semi-structured interviews with people with bowel disease (Chapter Five) and the nurses (Chapter Six). Chapter Five addresses physical activity counselling from the patient perspective and elaborates on the illness experience. Chapter Six explores physical activity counselling from the nurses' perspective and elaborates on current physical activity counselling practices.

The next chapter will introduce the first of three qualitative studies. Chapter Four is an ITA of online interactions about physical activity and exercise. It begins with a brief review of online health discussions and cancer-specific online discussion groups, followed by the methodology, results, discussions, and conclusion.

Chapter 4

Study one: Discussing exercise online

4.1 Introduction

Chapters One and Two introduced some of the physical and psychosocial challenges people with bowel disease experience, how exercise can provide benefits to mediate these challenges, and the current literature surrounding physical activity counselling that occurs between people with bowel disease and the healthcare professionals who care for them. Chapter Three discussed the methodologies implemented to explore this phenomenon. Due to the relative lack of research, more information is needed about discussions relating to physical activity for people with bowel disease. This is especially relevant to counselling that occurs between people with bowel disease and nurses, but it is important to initially understand the role that exercise plays from patients' perspectives.

This chapter reports on the first study of this thesis, which explored the role of physical activity for people diagnosed with bowel cancer, a specific type of bowel disease, and how this role influenced their experience with this condition. The literature review of this chapter discusses online health discussions specific to cancer and qualitative health research, followed by the rationale for this investigation. The methods are then explained and a detailed overview of the data analysis is described. Ethical consideration for this research is then reviewed. The results of this study are then presented, followed by a discussion of the results as they pertain to the current literature. Finally, a reflection of the data collection and analysis phase as a qualitative researcher is discussed, followed by the conclusion.

4.2 Background

4.2.1 Online health discussions and qualitative health research

Online health discussion groups are also known as online health communities, electronic health support groups, Internet health forums, computer-mediated health support groups, and online health support groups. Online health support groups are framed by traditional peer support health group structures and are grounded in the idea that the sharing of experiences will improve a range of outcomes for the members of the

group (Campbell, Phaneuf, & Deane, 2004). It appears that online health support groups are becoming an option for many patients with chronic disease, with the Pew Research Center reporting that 20% (N=2,253) of e-patients living with a chronic disease participated in some form of online discussion forum (S. Fox & Purcell, 2010).

Analysis of online health discussion forums has been used previously to understand communication in health care. For example, online health discussion analysis was applied to observe how people with diabetes shared information relating to health in online forums (Greene, Choudhry, Kilabuk, & Shrank, 2011). Results indicated that people with diabetes utilised the online platform to exchange information relating to disease management, and matters related to health that were unlikely to be discussed with their healthcare professionals. Such issues included how to safely consume alcohol for extended periods of time, and the physical demands facing triathletes with diabetes. This information was not likely to be discussed with healthcare professionals because it is highly personal and may be so specific that only people with diabetes may have such knowledge to share. In this instance, online discussions allowed people with diabetes to learn and exchange information from their peers' knowledge and experiences.

One potential matter not routinely clinically discussed between patient groups and healthcare professionals is exercise or physical activity. Physical activity behaviours and experiences are beginning to be investigated through analysis of online interactions and communication. For example, online qualitative analyses of Internet forums has been conducted to compare female minority groups' attitudes toward physical activity (Im et al., 2011 ; Im et al., 2010). These studies report that African American women identified exercise as a luxury and they indicated that they had missed their opportunity to learn about exercise during their youth (Im et al., 2011). It was also observed that Hispanic women identified other aspects in their life that they would prefer to spend their time doing rather than exercise, such as taking care of family and earning an income (Im et al., 2010). In these instances, online forum data was utilised to define exercise and also its value from the perspectives of two female minority groups. Such analyses of online data add information about the value of physical activity based on different ethnicities and minority experiences with physical activity.

The experience of living with disease has also been analysed using online health discussion forums. An analysis of online communities for people with arthritis demonstrated that self-management strategies utilised by some members influenced the self-management strategies of others (Willis, 2014). The type of information sought in online communities can also assist a broader understanding of the experience of living with illness and disease. For instance, simply participating in online health discussions can add to the knowledge surrounding the lived experience of disease (Ziebland & Wyke, 2012). The authors argued that the act of blogging or sharing illness experiences online has implications for researchers' understandings of the patients' perceived role in their own care and disease management.

Cancer survivors appear to utilise online platforms to communicate with each other, with these sometimes known as online cancer support groups. Such groups, typically separated by cancer type, are now being assessed by researchers to understand patient behaviour, illness experience, and communication (Asiedu et al., 2014; Rimer, Lyons, & Meier, 2005). Although not traditionally accessed in health research, the Internet and online discussion boards are information resources that may provide suitable opportunities for the collection of qualitative data relevant to improving the survivorship of many chronic disease patient groups (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003).

4.2.2 Cancer-specific online discussion groups

People diagnosed with cancer utilise the Internet to search for a range of information needs. This may include a need for supportive communication, gaining additional knowledge on disease-related information, and practical tips for daily living with cancer (Josefsson, 2005; Meier, Lyons, Frydman, Forlenza, & Rimer, 2007; Yli-Uotila, Rantanen, & Suominen, 2014). Cancer patients may also refer to the Internet to research more about their disease as well as other general health issues (Rimer et al., 2005) and to obtain additional information regarding diagnosis and treatments (Asiedu et al., 2014). Online discussion groups are also convenient and there is a high possibility of connecting with someone who shares the same diagnosis, management plan, symptoms, difficulties, and outcomes (Turner, Grube, & Meyers, 2001).

Online cancer support groups can also provide practical support. For example, an analysis of interactions within an online ovarian cancer community indicated that women with ovarian cancer commonly used the forum to discuss whether the health information they received from their healthcare professionals was honest and accurate (Gill & Whisnat, 2012). The members referred to the forum when their trust in healthcare professionals was low, such as dissatisfaction with healthcare professionals' suggestions to delay initiating treatment. They also shared information about diet, activities relating to daily life, and treatment side-effects. Therefore, online cancer forums provide a platform for people to discuss and advise each other on issues relating specifically to their cancer.

The advice received from online cancer support group members appears to be different from that received from healthcare professionals. Specifically, the information sought in online discussion boards might complement the advice received by healthcare professionals (Armstrong & Powell, 2009). However, one study suggested that the influences of other cancer patients' experiences were somewhat greater than those of doctors (Chiu & Hsieh, 2012). Therefore, members seeking support from similar others because of a lack of trust in their healthcare professional may be influenced more by the advice of similar others.

Analyses of online discussion forums revealed that they provide opportunities for members to communicate their experiences with similar others when they may not have been able to speak to those similar others face-to-face (Foster & Roff, 2009; Seale, Charteris-Black, MacFarlane, & McPherson, 2010; Turner et al., 2001). This included the ability to discuss intimate bodily symptoms that they may be embarrassed to discuss with their friends, family, or healthcare professionals (Seale, Ziebland, & Charteris-Black, 2006). For example, men with prostate cancer reported feeling able to discuss their uncomfortable and challenging experiences, such as urinary/bowel dysfunction and incontinence with other members of the online discussion group (Oster, Hedestig, Johansson, Klingstedt, & Lindh, 2013).

One major benefit of sourcing online discussions for research is to understand the experiences of diseases as they happen. Seale et al. (2010) analysed how people share

breast or prostate cancer experience in two different contexts, online and in face-to-face interviews. The authors reported that the online discussions provided a more recent telling of how patients were “doing their illness”, emphasising that there was a greater level of detail within online forums about how people were living with cancer, which included feelings about prognosis and diagnosis. More personal information, such as sexual health and thoughts of suicide, were also discussed in greater detail on the forum. These findings suggest an analysis of online discussion forums to understand the lived experience of disease provides a more nuanced account of the experience of illness in the moment and may be obtained through applying traditional qualitative methods online.

Few studies have researched bowel cancer online communities even though bowel cancer is the third most diagnosed cancer internationally (Ferlay et al., 2012) and in Australia (Australian Institute of Health and Welfare, 2015). Despite the frequency of its diagnosis and the large number of physical and psychosocial symptoms that affected individuals live with on a daily basis, bowel cancer commands considerably less public - and scholarly - attention in contrast to breast and prostate cancer (Van Mossel et al., 2012). Research advocates the benefits of physical activity and exercise for people with bowel cancer (Fisher et al., 2016; Husson et al., 2015; Van Roekel et al., 2015), yet little is known about how bowel cancer patients experience physical activity which, in turn, makes it challenging for healthcare professionals to provide effective physical activity counselling.

In regards to exercise, Courneya and Friedenreich (1997) noted that bowel cancer survivors tended to return to physical activity following treatment completion. However, reports on how people with cancer utilise the Internet to search for exercise-related content have been focused primarily on breast or prostate cancers. For example, one report suggested that many breast cancer survivors had searched the Internet and online groups for information about exercise unique to breast cancer (Trevino et al., 2012). This implies that people with cancer are open to seeking exercise information, support and advice from online cancer support groups. As people with bowel cancer appear to return to physical activity after treatment, it can be implied that they value exercise as part of their lives. However, the degree to which bowel cancer survivors utilise online support groups to search for exercise-related information remains mostly unknown. Therefore,

this investigation explored this phenomenon further to understand the specific value of exercise for people with bowel cancer. This study applies an inductive thematic analysis (ITA) to messages exchanged online to explore members' experiences with exercise and physical activity, specifically their views, opinions, and beliefs surrounding exercise and how these messages are developed and conveyed to each other. This is similar to the methods deployed by Malik and Coulson (2007), which explored the male experience in infertility through inductive analysis of an online support group. These are important characteristics relating to the ways in which people with bowel cancer will approach counselling related to exercise and physical activity.

4.3 Method

4.3.1 Study design

The research question, how people with bowel disease discuss exercise among themselves, was addressed using an ITA of online asynchronous archived discussions on a bowel cancer discussion board. Asynchronous discussions were chosen because they provide the greatest insight into authentic communication among bowel cancer survivors while reducing any potential harm to the members of the community and the discussions.

4.3.2 Selection of materials for analysis

A search of online bowel disease discussion groups was conducted by searching the keywords "bowel cancer", "Crohn's disease", "ulcerative colitis", "inflammatory bowel disease" "IBD", "online forum", and "online support group". The Cancer Survivors Network bowel cancer discussion board run by the American Cancer Society was selected for analysis. Compared to other online discussion forums, the American Cancer Survivors Network was selected because it is one of the largest online cancer forums (Portier et al., 2013) and is available internationally. International availability increases the potential of reaching a wider demographic in regards to age, ethnicity, and information specific to disease such as years since diagnosis and current stage of disease. This wide reach also maximised the number of interactions potentially available for analysis. Most importantly, this discussion forum was chosen because the website

unequivocally states that any information posted onto the discussion boards is publicly viewable (Figure 4.1).

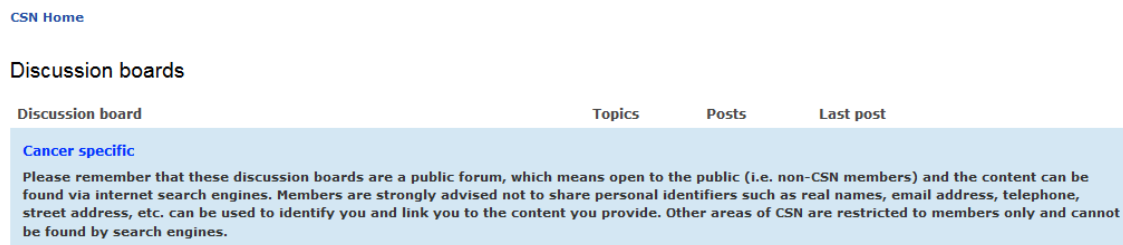


Figure 4.1. Public disclosure notice of cancer specific discussion boards

Other online bowel disease groups, including online inflammatory bowel disease support groups did not display an easily visible disclaimer or did not have a disclaimer at all. This is an important ethical consideration, which will be discussed in section 4.3.5. An open access public forum was utilised because researcher-mediated message boards may lead to potential response bias; fewer individuals may join such groups, and therefore, some people may not fully express their opinions on some topics. Additionally, should participants receive an incentive, participants may be inclined to participate to receive the incentive only without due process to the topic at hand as was reported in a researcher mediated online discussion forum on cancer pain (Im & Chee, 2006). The benefit of using open access public non-mediated online message boards is that the participants discuss issues relative to them when they are relevant in the disease trajectory, thereby maximising visibility of their perceptions on the impact of disease in everyday life.

An asynchronous discussion board was chosen because this type of communication enables members to interact at a time and place convenient to them (Wright, 2000). Additionally, posting on a discussion board allows all members to read and respond to a message thread, even though it may have been originally posted many days, weeks, or years previously. Furthermore, participants may search message threads using keywords to locate and read information relevant to their current information needs, with these individuals being the primary users of discussion boards (Chung, 2014).

At the time of data collection, the discussion board consisted of 280,356 posts. Keywords such as “exercise”, “physical activity”, “moving”, “walking”, “lifting”, “weights” “training” and “resistance” were used to search for threads relating to exercise or physical activity. A “thread” is the title of the discussion topic (Figure 4.2), while “posts” are the discussions that occur within a thread (Figure 4.3). A keyword search identified search terms within posts. A title search identified search terms in the title of the thread. Where keyword search terms identified words of different meanings, the online data were read to ensure that no discussion of physical activity or exercise took place and the online data was removed from the analysis. For example, a keyword search of “resistance” included posts and threads relating to medication resistance. Such threads were therefore discarded as the topic was unrelated to physical activity.

CSN Home > Discussion boards > Cancer specific

Search by keyword Search by Title

Threads **Colorectal Cancer**
[Login](#) to post new content in the forum.





Topic	Replies	Created	Last reply ▾
 Question re survival	7	May 20, 2015 - 3:43 pm by Girl2	May 20, 2015 - 11:18 pm by NewHere
 Tell me about port removal, please	26	May 15, 2015 - 5:08 pm by JanJan63	May 20, 2015 - 10:50 pm by NewHere
 Has anyone done a IV vitamin drip the day before chemo	1	May 20, 2015 - 11:10 am by lilpep1972	May 20, 2015 - 10:45 pm by Trubrit
 Cea	12	May 20, 2015 - 6:29 am by Girl2	May 20, 2015 - 10:19 pm by Annabelle41415

Figure 4.2. Examples of threads in a colorectal cancer discussion forum



Figure 4.3: Example of posts within a thread

The Cancer Survivors Network discussion board was open to individuals currently being treated for bowel cancer, survivors of bowel cancer, caregivers, partners/spouses, and other family members of people with cancer. Only threads initiated by patients and survivors of bowel cancer were included in the analysis, as the research question aims to answer how people with bowel disease, including individuals with bowel cancer, discuss exercise. This created an opportunity to explore issues and concerns relevant to those living with cancer or as a cancer survivor through threads initiated by them. Inclusion criteria required threads to:

- be initiated by a person currently or formally diagnosed as having bowel cancer
- include posts relating to physical activity or exercise.

Discussion threads introduced by partners/spouses, caregivers, or others were excluded. A search of the online discussion board yielded 139 threads. A search by keyword identified 102 of the threads, while a search by title identified 37 threads.

4.3.3 Data collection

The member who initiated the thread assigned a title to it. Threads are utilised as indicators by other members to identify the contents of the thread. As discussed in Chapter Three symbolic interactionism guided data collection. Each thread was read online to establish if it met the inclusion criteria. Following a review of all the selected threads, they were organised chronologically based on the date of the thread. Threads were dated from March 4, 2003, the earliest thread relating to physical activity or exercise, to July 11, 2014, when data collection ceased. The first thread date of March 4, 2003 was after the benefits of exercise for bowel cancer were documented in peer-reviewed literature. The benefits of exercise for bowel cancer patients has been recognised within the literature since 1999 when Courneya, Friedenreich, Arthur, and Bobick (1999) published one of the first studies investigating the benefits of exercise for people diagnosed with cancers other than breast. This meant that date restrictions on threads were not warranted because knowledge of the benefits was available as of 1999.

4.3.4 Data analysis

ITA was conducted following the recommendations of Braun and Clarke (2006). This method identifies themes and patterns across a data set. For this analysis, ITA was completed manually. This process was described extensively in Chapter Three. As a result, this section will provide an example of how initial codes, specific to this analysis were grouped into provisional themes and then into final themes (Table 4.1). Further examples can be seen in Appendix A.

Table 4.1

Example of the development of a final theme

Initial note	Initial code	Provisional theme	Final theme
<i>sanity</i>			
<i>reconnecting with life</i>	<i>Spiritual benefits</i>		
<i>inner calm</i>			
<i>healing process</i>			
<i>manage side effects</i>	<i>Physical benefits</i>	<i>Exercise provides</i>	<i>Cultural value of</i>
<i>the best medicine</i>		<i>holistic benefits</i>	<i>exercise</i>
<i>complimentary</i>			
<i>treatment</i>	<i>Medical benefits</i>		
<i>holistic approach</i>			

Meetings with the principal supervisor occurred where potential final themes were discussed based on the initial codes. Following the recommendations of Braun and Clarke (2006), the final themes were then checked to ensure they encompassed the entire data set and the general narrative of the analysis. Initial notes and initial codes were developed across 96 threads where data saturation occurred. This occurred when reading further posts did not yield any new themes. To confirm data saturation, the researcher read through three more threads to confirm all the main themes had been established and no new themes could be extracted.

4.3.5 Ethical considerations

This research was approved by the Bond University Human Research Ethics Committee RO-1882.

Traditional research ethics guidelines dictate that researchers must take the necessary precautions to ensure the privacy and confidentiality of data as well as the collection of informed consent of all participants (Buchanon & Zimmer, 2015). It is

argued that information posted in a public discussion group is a public act and therefore available for public consumption which requires no more than the usual precautions (Mann & Stewart, 2000). Eysenbach and Wyatt (2002) reported a “passive analysis” of online data collection does not mandate informed consent. A passive analysis occurs when the researcher strictly observes the interaction and communication of a public online space. This research did not actively engage with members of the online community and was therefore classified as a passive analysis of the data and therefore, followed the ethical exemption model as described by Robinson (2001) (Figure 4.4).

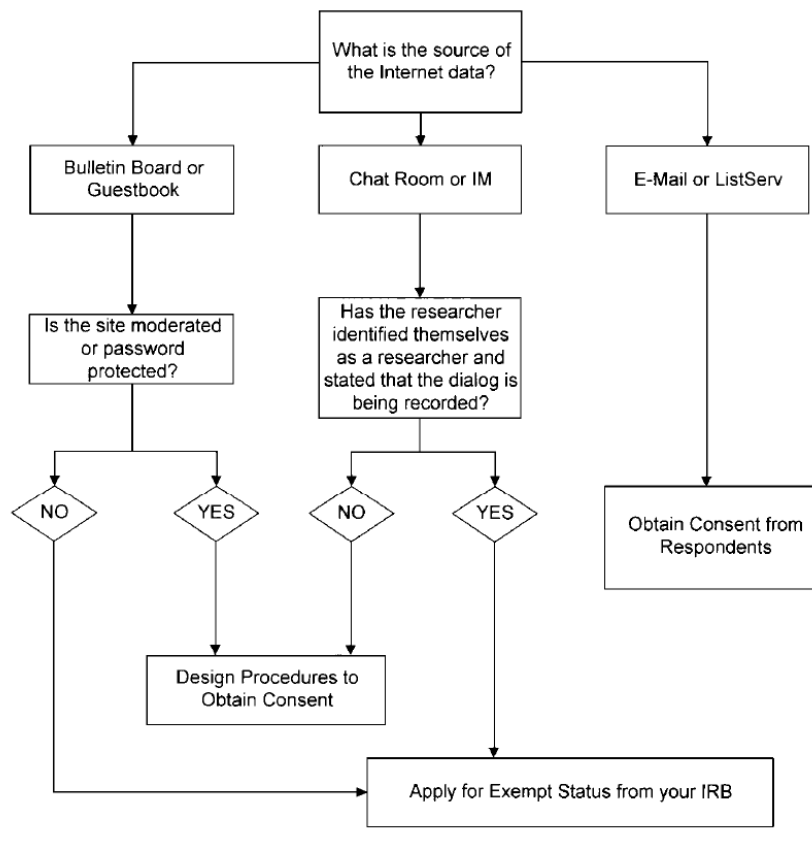


Figure 4.4. Exemption decision model for unsolicited narrative data from the Internet

Note. From "Unsolicited narratives from the Internet: A rich source of Qualitative data," by K.M. Robinson, 2001, *Qualitative Health Research*, 11(5), p. 710.

Gathering informed consent to explore archived communication of an online asynchronous discussion board is difficult. It involves joining the discussion group,

identifying oneself as a researcher, and asking for permission of the members to analyse the archived discussions. Introducing a researcher to the community may disrupt and alter the dynamic of the community, an act which may be seen as disruptive and, therefore, unethical. Additionally, receiving permission from only selected members of the community would mean that only threads in which each member gave permission could be used for analysis. This approach minimises the benefit and potentially maximises the harm of the investigation which is also viewed as unethical (The British Psychological Society, 2013).

However, members of these online communities may feel the information they post to the forum or discussion board is private. With this in mind, the researcher identified a discussion board in an online community which made the public nature of the posts explicitly clear to anyone who posted on the discussion forum. Moreover, it was not required to be a member of the community to view the content on the online discussion board, as it was publicly accessible at the time of collection. This means that viewing the contents of the online discussion board did not require passwords.

In compliance with the Bond University Human Research Ethics Committee, members' posts have been recited verbatim in this thesis only. This is done to allow the researcher to fully demonstrate the analyses of the discussion content for examination purposes. However, any publications and conference proceedings from this study will utilise paraphrased quotes from members of the online forum.

4.4 Results

ITA of the threads yielded seven themes. *Faith in the knowledge of the benefits of exercise* indicated that members felt both disappointment in exercise for not keeping them cancer free, but also that exercise kept them healthy following diagnosis and treatment. *Cultural value of exercise* revealed that forum members were discussing the spiritual benefits associated with exercise, the physical benefits that exercise or physical activity provided them, and the medical benefits they received from it. *Responsibility to oneself and others to be active* encompassed community and individual feelings of responsibility to become and/or remain active. *Preserving identity* revealed that forum

members held onto a piece of their pre-diagnosis self by using exercise and physical activity as an expression of who they were. *Calibre of exercise* identified the varying levels of intensity with which members felt defined exercise or physical activity. *Readiness to participate in exercise or physical activity* encompassed the range of willingness members expressed about becoming more physically active and voicing this to other members of the group. Finally, *levels of encouragement* revealed the varying levels of passion members of the discussion board held when encouraging fellow members to become or remain physically active.

4.4.1 Theme one: faith in the knowledge of the benefits of exercise

This theme describes some members' disappointment in their belief that exercise would have kept them cancer free, but at the same time speaks to the faith they have in the ability of exercise to help the recovery process. One member experienced a level of disappointment and voiced cynicism about published research based on their experiences. This member writes:

Thank you for an interesting item, I have to admit I look at these studies with a jaded eye now. I was exercising (brisk walking or swimming, strength training and yoga) regularly for years (20 or more) and eating my nine servings of veggies/fruit per day. My co-workers would make fun of me. I ate very little red meat (Once a month or less). Yet I still came done with stage 4 rectal CA.

Thread 7, Post 3. Lines 2-4.

This member expressed feelings of defeat, which may have had negative implications for whether this person would begin an active lifestyle after treatment. Such perceptions may have also influenced the manner in which this individual engaged in any future discussions about activities with either other members or healthcare professionals. This individual appeared to have developed negative feelings towards exercise. Other members of the forum expressed similar sentiments. They wrote:

I too was very active, walking 5 miles each morning, eating healthy- all the things I thought would keep me healthy - luck of the draw I guess.

Thread 2, Post 2. Lines 7-8

and:

It's funny though, you take care of yourself, try and eat right most of your life, work out physically and cardio, maintain your weight throughout your life and blamn, 2006 cancer and 2010 could be looking at a pace-maker in my retirement years. Then you have people that are overweight, obese, don't watch what they eat, don't exercise, smoke, drink etc., and blamn, never a health issue. Scratch head and go figure :) :) :) :) LOL!!!!!!!!!!.

Thread 57, Post 1. Lines 11-14

These statements expressed a disillusion that exercise would keep cancer at bay or provide protection to developing the disease. Thread 57 demonstrates a degree of frustration in which those who did not participate in healthy behaviours appeared to be unaffected by the consequences of their choices.

However, other members of the forum did not express these statements of disappointment. Some members shared their experiences about how they also exercised before diagnosis but did not blame exercise for not keeping them cancer free. One member wrote:

I have exercised most of my life before (not much during) and after cancer. Even if it didn't help stop the beast, which I do believe it does, I would still do it.

Thread 22, Post 10. Lines 2-3

This statement demonstrates a positive outlook and that being diagnosed with bowel cancer did not change the attitude or value of exercise. Another extract explained:

My doctor told me there would be a 95% chance that the cancer would return. I asked him what I could do to prevent reoccurrence. He told me exercise. That was no problem for me as I have always exercised.

Thread 58, Post 1. Lines 6-7

For this member, bowel cancer and survivorship appeared to have no influence on the attitude towards exercise. It would seem that the diagnosis had been accepted, treatment completed, and this member was now working on incorporating exercise as a tool to improve their chance of survival, as according to their doctor, that was the way to do it. This statement demonstrates some of the unchanged attitudes some members of the forum had towards exercise following their diagnosis. This member may not have known that exercise had been reported to reduce the risk of bowel cancer and; therefore, did not express feelings of defeat after their diagnosis. Alternately, if this member was aware of this evidence about the benefits of exercise, they may have chosen to move forward in survivorship without feeling let down by misplaced faith.

Commonly, members of the forum had faith in their knowledge that exercise would help them in their recovery. One member who was feeling particularly anxious about the one-year follow-up scan posted:

I am happy about this scan but know that if I have a recurrence I will fight it again. In the meantime, I continue to hug my significant other and children every day, exercise every day, juice every day and take vitamin D.

Thread 51, Post 1. Lines 4-5

This member indicated that exercise had become a part of a daily routine to stay healthy. Exercise had become a part of a survivorship plan in which the intention was to continue to maintain their health through engaging in healthy behaviours that included physical activity. It can be speculated that this individual placed a high value on the benefits of exercise to maintain health.

4.4.2 Theme two: cultural value of exercise

Each member of the forum held different interpretations of exercise based on different cultural beliefs and backgrounds. Bowel cancer patients discussed the cultural value of exercise as having spiritual, physical, and medical benefits. The contributors to the online forum casually shared these benefits with other members. Physical benefits indicated the positive effects that exercise had on general symptomatic aspects of cancer and were expressed by statements such as:

We also exercise most every day and participate in yoga several times a week. I really believe that all this has helped me manage side effects, reduce tiredness, rebound to feeling 'normal' again, etc.

Thread 46, Post 6. Lines 4-5

and:

I exercise one hour every morning, walk 45 minutes in the afternoon, and practice 'chi gong' 1 to 2 hours in the evening. This daily routine keeps my spirit and energy levels high. It also makes the chemo more tolerable.

Thread 23, Post 1. Lines 11-13

These two extracts demonstrate that members shared with others how exercise was helping them cope with their cancer treatments. These posts expressed the value that exercise had during treatment because it was contributing to decreased feelings of fatigue and eased the discomfort caused by cancer treatment. Here, these members described how they had a better response to the symptoms of bowel cancer and the treatments because of exercise. Additionally, Thread 23 illustrates how forum members also experienced the spiritual benefits of exercise. Other members shared the exercise benefits they received in a more general sense:

I was encouraged to walk a lot after the surgery, and I did - I think this helped my recovery.

Thread 4, Post 4 Line 2.

and

Walk as much as you can - walking will help the healing process.

Thread 8, Post 5. Line 7

These two separate posts demonstrated that forum members had positive experiences with exercise in relation to bowel cancer and were sharing these experiences with other members of the group.

Others talked about exercise as a form of complementary medicine or the medical benefits and acknowledged that:

While it may feel that your wife is ratting on you, I think that she is aware that walking is the best medicine for you.

Thread 62, Post 2. Lines 5-6

Here, this member related exercise to a form of medicine or treatment for bowel cancer. A different member reciprocated this view:

I view my exercise and my diet and meditation as an extension of my treatment.

Thread 94, Post 6. Line 16.

Members posted about exercise in clinical terms by using words like “*medicine*”, “*treatment*”, “*holistic*”, and “*vital*”. The members were using these terms to describe the value exercise had during and following treatment. This suggested that these members valued exercise and physical activity as medically necessary to their recovery and had adopted a more active lifestyle as part of their medical treatment in the same way as one undergoes chemotherapy or radiotherapy when recommended by their oncologist.

4.4.3 Theme three: responsibility to oneself and others to be active

This theme was demonstrated by the online community's desire to help other members keep active. Examples include declarative statements such as:

We have to spread the message about exercise and preventing reoccurrence

Thread 70, Post 36. Line 2.

This post and similar others inspired other members to post a description of their physical activity and exercise programmes. This sense of responsibility to be active was also felt within the individual.

One member wrote:

...just curious to as to what other people who were active before surgery/chemo/etc. are doing now – how soon, how much and how often – compared to life before cancer?

Thread 21, Post 1. Lines 6-7.

This member was seeking advice from those who have been there before, a common occurrence on the forum, to adapt to his/her own care.

In response to adding walking to their activity program one member posted:

I will continue to exercise (I've been building strength and can now do an hours worth when I have the time) I may consider adding walking soon. It will have to be on my treadmill, since I'm reluctant to get far from the br [bathroom] (even the treadmill is far away, but at least it's in the house). I will do what I need to beat this.

Thread 7, Post 2. Lines 88-90.

This statement identified the level of commitment and responsibility to survive, and the important role that exercise had as a part of that commitment and responsibility.

Part of the forum contributors' responsibility to oneself and others was being proactive in their own care either by consulting others or by doing their own research. One member responded to another's post about staying active by writing;

It sounds like you're being very proactive about your cancer. I'm really glad you didn't listen to the first opinion. It pays to be persistent, doesn't it?

Thread 33, Post 2. Lines 1-2.

This extract illustrates the encouragement members of the forum expressed towards each other in regards to taking accountability for one's health. Being proactive also included members of the forum telling other members to explore other sources of information. For example:

I initially went to the osteo docs [orthopaedic] simply to get a physical therapy appointment to learn how I can exercise without killing myself.

Thread 24, Post 1. Line 5.

Another member posted:

I found an online study which says walking one hour per day will improve our chances by having a positive impact on those cells that clean out cells which might decide to become cancerous. So today is the day to start that one hour walk.

Thread 74, Post 13. Lines 1-3.

These messages imply that survivors and patients consulted different information sources in their efforts to learn about exercise. They were proactive in their search for more information. This suggested that exercise plays a central role in the recovery process and

survivors access information from less traditional sources such as members of the online community.

Members also expressed a responsibility to themselves to become physically active by expressing a desire to retake control of their bodies and their lifestyles. They stated a need to regain this control through diet and exercise and communicated with each other the important role exercise had in recovery. Exercise appeared to help members take responsibility for their health. This is illustrated in the following extract:

My regular running regimen went way down, but I hung on and did something every day, even walking laps of my yard on some of my weakest days. The movement helped me sleep at night and feel like I was doing something good for myself, something apart from my fight with cancer.

Thread 22, Post 1. Lines 3-5.

This statement explains that exercise was something that was non-negotiable. Exercise helped this bowel cancer survivor claim the responsibility of being healthy outside of solely fighting cancer. To this member, exercise played a considerable role in helping him/her maintain a responsibility to care for oneself.

4.4.4 Theme four: preserving identity

New members introduced themselves to the forum by including previous athletic identities and indicated the importance of this identity. One member posted:

I've already read Lance Armstrong's books and I really want to keep positive throughout my treatment. My children are young and still need me, my daughter was diagnosed with Lyme's disease four days after I came home from the hospital. No recovery time for MOM. I would like to know if anyone has suggestions for books on nutrition and exercise during cancer. I am quite the fitness enthusiast and am going stir crazy with my little ¼ - ½ mile daily walks that I am performing now.

Thread 2, Post 1. Line5-8.

This member reported feeling unsettled because of their inability to do more than what they considered to be a small amount of physical activity at the moment and was seeking advice from other members of the group. To this member, cancer treatment and disease had influenced their ability to participate in their regular exercise routine. The extract identified someone who was active before diagnosis and expressed that what was defined to be limited activity was not enough for someone who identified as a “fitness enthusiast.”

Another individual’s introduction to the online forum was similar; however, this member maintained a secure sense of self and identity and exercise was the pathway that validated a return to self. The post states:

I too am and was a fitness freak (running/walking/weights/yoga daily) and almost went insane after my surgery not being able to do as much...but, I am now back to almost my normal routine and it makes a HUGE difference in how I am feeling both mentally and physically.

Thread 2, Post 8. Lines 5-6.

This member strongly identified as one who exercised, but did not indicate feeling disappointed by the lifestyle choice or that cancer and treatment had threatened their identity. For this individual, exercise was seen as a way to return to the usual self, or a way to measure a return to previous self. The two previous statements were in the same thread. This suggested this member sympathised with the first poster but indicated that they had returned to their normal routine. This member shared an experience to show that cancer and its treatment do not have to challenge the identity of self. Another member wrote:

I was a vegetarian and STILL exercise often. I am a very healthy cancer survivor.

Thread 5, Post 5. Line 5.

This statement was in response to a member who was struggling with their diagnosis. By posting as a healthy cancer survivor, it was implied that “healthy” and “cancer” were not

opposing terms and in fact, one could be both. For this poster, cancer did not define who they were as a person, but rather something to overcome. This person identified as someone who was active and cancer did not take that identity away.

When preserving identity was important to some members of the forum, these individuals' beliefs were clearly stated to the group. This influenced the feelings of many of the members and contributed to the foundation of some of the other themes. For example, Thread 2 influenced other members' perceptions of how much activity constituted exercise or the calibre of exercise. Similarly, members who were unable to walk a short distance or those that felt proud of their achievements if they were successful in completing short distance walks began to question their efforts. This may have contributed to some members expressing their lack of confidence in participating in exercise.

4.4.5 Theme five: calibre of exercise

This theme indicated that members of the forum held different ideas of what defined exercise and what kinds of exercise provided a health benefit. One post in the forum reads:

People can have work that requires difficult physical labour for decades and still have their health deteriorate as they age, because they haven't been doing the right kinds of exercise. I watched my mother's health go in two years, despite her active life and very healthy eating habits --she gardened and did yard work, and walked, but she never ran, or cycled, or swam.

Thread 29, Post 17. Lines 3-6.

This member believed that there were correct types of exercise that preserved health, when, in fact, gardening, yard work, and walking can improve clinical outcomes. Some members were sceptical of what exercise or physical activity could help recovery and held the belief that because it was not the correct kind of exercise, there would be no benefits. This belief discouraged other members because it pushed the view that running, cycling, or swimming, were the only beneficial forms of exercise/physical activity.

Another member encouraged the group to:

Post every day, every time we do meaningful exercise. It's good for healthy, the soul and recurrence prevention.

Thread 71, Post 5. Lines 1-2.

Thread 71 invites the forum contributors to become part of a collective group of exercisers. This thread encourages an alliance among those that engage in exercise behaviours. However, the term “meaningful” is subjective; therefore, members of the forum will interpret it differently. As a result, they may begin to question their exercise efforts and share their exercise experience to the group based on whether other members of the forum agree that the physical activity they engaged in was “meaningful.” The description of what does or does not constitute as exercise was commonly discussed among members of the group. One post explained:

I am trying to find 'the perfect' diet and exercise plan so I can help my body beat this and recover. I am just curious if any of you have followed anything specific... at this point I am a bit overwhelmed! Any ideas?

Thread 30, Post 1. Lines 3-6.

This suggests that this contributor was concerned with the idea of constructing a faultless survivorship plan, perhaps intensified by posts that discussed what was perceived to be correct or appropriate exercises. This pressure may have discouraged this person to begin any physical activity because their plan might have been viewed by others as flawed because it did not meet the other’s standards of what constituted exercise.

This view was not held consistently across the group, as a range of opinions emerged within the interactions as to what level of exercise was required to receive benefits. For example:

I try to swim and do exercises 5 times a week, can't run or anything else but it all helps.

Thread 64, Post 43. Lines 9-10.

This member indicated that they participated in some form of structured exercise but also believed that every little bit of physical activity counted even if participation in other forms of structured exercise was limited. Another post explained:

We try to have Friday night date night at a local restaurant and we walked there. Hey, it's something!"

Thread 70, Post 45. Lines 2-3.

This individual accepted that, although there was no engagement in any vigorous form of exercise or physical activity, some type of low intensity physical activity could still be achieved. This individual appeared to believe that even small amounts of low intensity exercise could outweigh some of the consequences of physical inactivity.

4.4.6 Theme six: readiness to participate in exercise or physical activity

This theme identified the forum contributors' willingness to become more physically active. This was demonstrated through posts that related to the reflections of personal capabilities by many of the members. For example, some expressed their reluctance to participate based on their beliefs about their readiness. This was indicated when one member posted about seeing the surgeon during a check-up:

It's great to hear other people's experience with this. I was hoping I could start sooner but I am also concerned about doing too much too soon. Last time I saw the surgeon I didn't feel good enough even to raise the question. Next time I see him I will though.

Thread 16, Post 3. Lines 2-3

This member expressed a desire to start physical activity; however, asking the surgeon about exercise required a level of preparedness that this individual seemed to have not yet achieved. This idea of feeling good enough should be explored further to understand the physical, as well as the mental preparedness that some people might perceive as being required before adopting a physically active lifestyle during or following disease.

Other members felt disappointed and ashamed of what the disease had done to their bodies. One statement highlighted a barrier to being physically active by writing:

I have tried to exercise on the treadmill but 5 minutes doesn't hardly seem to be worth the trouble to put on my tennis shoes.

Thread 36, Post 1. Lines 6-7.

Here, the member identified a desire to become more active, but the accompanying toll that the disease took on the body and the inability to perform exercise for a perceived sufficient amount of time, diminished this preparedness. This extract may demonstrate a low level of readiness to exercise because of the inability to be active for longer than five minutes instead of viewing the five minutes as a starting point that could be used to inspire six minutes the next time and seven the time after that. The degree of a person's readiness to participate in exercise activities relied on understanding the definition of exercise.

Other members of the forum expressed a desire to engage in physical activity and were more prepared to participate in exercise. One member stated:

I have been totally unmotivated about losing weight, which I really need to change.

Thread 6, Post 18. Lines 2-3.

This suggested that this person had become unhappy with their weight gain and had identified that a change in motivation needed to occur in order to lose weight. Recognising a change needed to occur, specifically a change in motivation, this individual had already contemplated a solution to losing weight, which indicated a level of preparedness to engage in some physical activity. Another statement explained:

I'm still thinking of joining our local gym so I'll feel more compelled to try to go exercise.

Thread 27, Post 7. Line 3.

This poster indicated an understanding of the importance of exercise and had followed the thought processes that joining a gym would influence activity. This was a personal motivational technique of this poster that would be implemented in hopes of becoming more physically active. This person had found a potential solution to a barrier to exercise, which demonstrated a level of willingness to participate in exercise. Another member said:

I joined a gym about 2 years ago. I need to find time to get there more often.

Thread 22, Post 9. Line 1.

This statement identified a barrier to becoming more physically active, which was time. It is well known that time is a very common barrier to exercise and it was obvious from this poster that time was a barrier to exercise for people diagnosed with bowel cancer. However, this poster had yet to identify how to find the time to go to the gym regularly.

Other members of the online community that expressed a readiness to participate in exercise reached out to the group to seek exercise advice. One member wrote:

Has anyone had any concerns about exercising their upper body with the chest port in place? Are there any restrictions to activity?

Thread 50, Post 1. Lines 1-2.

This forum member had sought advice from those with similar experience. The member was interested in exercise and showed an understanding of the risks associated with exercise and was, therefore, looking for advice from similar others. Another statement read:

Thank you ----! Such great information. It is great to know that others have gone through this before! I will take your advice re: prunes etc. I need to start my exercise back now!

Thread 78, Post 5. Lines 1-2

Here, the forum was a platform with which individuals with bowel cancer expressed varying levels of willingness to engage in physical activities by sharing their questions and concerns. The forum was also a source of information that had the potential to influence an exercise routine and motivate change.

4.4.7 Theme seven: levels of encouragement

Levels of encouragement encompassed a range of motivational posts aimed at inspiring forum members to become physically active or maintain a physically active lifestyle. This theme varied from the extreme:

So I'd like to remind you that however excellent your reasons for not exercising, those reasons will not preserve your health. It's not a moral issue. Try to find a way.

Thread 29, Post 17. Lines 6-7

to:

Take it slow, one day at a time and the next thing you know, you'll be running on that darn treadmill.

Thread 42, Post 10. Lines 1-2

These two posts highlighted the varying degree to which members of the forum supported each other as well as the ways they wrote to each other. Perhaps the anonymity of the online platform was partially responsible for the critical post suggesting excuses for inactivity will not maintain health. Some members appeared to be offended by the unsympathetic post and it became a source of conflict. This was demonstrated when the member, who initiated thread 29 wrote:

I think if you re-read my babbling post, I stated I was reporting on observations that I NOTICED this weekend. Nowhere in the post did I say "Help! I need your advice on what to do because I have never heard of this word 'exercise' before! What is it???" Yet somehow you read into it that I was in need of your one-line advice. Gee, thanks for that...and I'm sure when/if we get the pain under control and I report back that I am now excited because I am actually able to start up an exercise regime of some sort in my life, this will please you to no end that I have taken your advice.

Thread 29, Post 18. Lines 10-14

This post suggested that the offended members considered the post threatening to their character by suggesting those members who were not exercising were lazy and not doing everything they could to survive. This level of encouragement made those who identified as not being prepared to exercise less likely to do so, as they have been discouraged from sharing the difficulties and barriers they encountered while trying to increase their activity levels for fear of appearing unwilling to preserve their health.

On the other hand, some forum members took a much gentler approach to encouragement by writing:

I have always been interested in chi gong (qi gong) too but did yoga instead and visualized during it getting rid of all those cancer buggers in my bod. I firmly believe in your routine.

Thread 23, Post 20. Lines 4-5.

The owner of this post identified with the efforts of the other member and although they chose a different physical activity, the poster demonstrated an encouraging attitude towards this member's plan. The target of this post received affirmation from another that their routine had been accepted.

Another way exercise was encouraged to members of the group was by sharing stories about personal experiences. One member made the following recommendations:

As far as exercise goes. Just get up and move whenever you can, and not more than you can. Even a little walk around the house or yard is better than being a bump on the couch. The more I moved the better I felt, etc... There were days I wanted to be a bump on the couch. But I would get up and walk the dogs around the block, and it would turn into several laps around the block. (I was afraid to be away from the bathroom and not make it. Which also did happen, lol.) I would also get out to the store to pick up one item, just to get out and get moving. Whatever can motivate you, do it.

Thread 76, Post 6. Lines 2-6.

This shared personal experience with exercise was a way to relate to other members of the group who may have felt discouraged about exercising or becoming more active. This story included examples of what worked when incorporating exercise and physical activity into a routine to inspire others to find what motivates them.

This theme highlights the value of exercise for some people with bowel cancer, demonstrated by their eagerness to encourage others to participate in exercise activities. However, this eagerness appeared to some members to be offensive. This illustrates the range with which people with bowel cancer valued exercise as part of their recovery and survivorship plan. This theme also draws attention to the different ways people with bowel cancer communicate with each other about exercise.

4.5 Discussion

An ITA of an online asynchronous bowel cancer discussion board identified several ways in which exercise and physical activity are present in the lives of people diagnosed with bowel cancer. Furthermore, this analysis identified the ways in which individuals diagnosed with bowel cancer communicate with each other online regarding exercise and physical activity.

This analysis recognised that exercise was an important component in the lives of people diagnosed with bowel cancer. Such a finding provides an understanding of one of the research questions, the perceived role of exercise for people with bowel cancers. This was expressed within the first theme, *faith in the knowledge of the benefits of exercise*. The forum members shared their negative and positive experiences and views towards exercise with each other in the online discussion board. This theme explained that people diagnosed with bowel cancer have a complicated relationship with exercise because members shared their anger towards physical activity and exercise for failing to keep them disease free, but also shared their belief that exercise would help them in their recovery. Similar results were reported during focus group discussions with people with bowel cancer in the United Kingdom, which revealed that they felt anger towards medical explanations connecting poor lifestyle to bowel cancer (Anderson et al., 2010). Shaha and Cox (2003) reported that people receiving a bowel cancer diagnosis experienced fear and anxiety, which lead them to question their choices, goals, and attitudes towards life. This is similar to what was demonstrated in this theme because members of this particular forum questioned their attitudes and beliefs about the goals they had set for themselves in regards to living a healthy lifestyle through exercise and physical activity. To the forum

participants, bowel cancer challenged this goal by way of threatening their identity. However, these feelings were not uniform for all members. Others chose not to question their beliefs about exercise and continued exercising through the illness experience. In this way, the role of exercise transformed from reducing disease risk to improving the illness experience. These members trusted exercise to help them move forward. It is understood from this theme that people with bowel cancer have a variety of negative and positive views in regards to the role of exercise in their lives.

Exercise was also perceived to provide a variety of benefits to those who were physically active and this information was shared among the members of the online forum. The *cultural value of exercise* theme identified that members of the forum categorised these benefits across the spiritual, physical, and medical domains. Similar results were indicated by women diagnosed with gynaecological cancer who exercised as part of their spiritual practice; however, due to the quantitative nature, i.e. spirituality measured utilising quantitative sub-scales, the significance of exercise in relation to the illness experience was not fully explored (Lopez, McCaffery, Griffin, & Fitzpatrick, 2009). It can be speculated from the analysis of this online forum study that exercise provided these bowel cancer survivors with a feeling of purpose by providing a pathway for reconnecting with their mind, body, and/or soul, with this contributing to improved health and wellness. Members of this forum discussed the ability of exercise to reconnect them with life and about their heightened feelings of calmness experienced following exercise. This is supported by research on another sample of people diagnosed with rectal cancer who participated in preoperative exercise and reported that exercise gave them a sense of purpose, thereby assisting with their ability to perform their usual activities (Burke et al., 2013). For the people with rectal cancer, exercise improved one aspect of their lives that led to the improvement of another. Members of this online forum in the current study wrote about similar relationships in their posts to each other about the spiritual benefits of exercise.

The members of the forum also discussed the physical benefits of exercise, many of which are consistent with existing literature. For example, one qualitative enquiry into the exercise experiences and preferences of bowel cancer survivors who completed a 12-week individualised exercise intervention, reported improvements in strength, aerobic

fitness, and endurance (Spence, Heesch, & Brown, 2011). The reported physical benefits of the 12-week exercise intervention were similar to the benefits the bowel cancer members discussed in this online discussion forum. This is an expected finding which demonstrates that exercise and physical activity can improve many aspects of physical fitness for people diagnosed with bowel cancer. The results of this analysis support the current knowledge within the existing literature surrounding the physical benefits offered by exercise for people with bowel cancer.

One key finding of this analysis was the language that members of the forum used when discussing exercise in terms of medical benefits. The forum members used terms generally reserved for standard cancer care. Exercise was referred to as an extension of treatment or another side of treatment. Many viewed exercise as part of their standard care. This information adds to the understanding of the position of exercise in cancer care and cancer survivorship from the patients' perspectives. It can be inferred that healthcare professionals hold similar views based on discussions that the bowel cancer community had about the role of their healthcare professional in discussing exercise with them. This question will be answered in Chapter Six, where exercise for people with bowel disease is discussed in interviews with nurses who care for people with bowel disease.

Members of the forum shared the benefits they received from exercise within the group to encourage others to participate. *Responsibility to oneself and others to be active* encompassed feelings of personal responsibility to be active as well as a community or peer responsibility to support others improve their health and well-being by becoming more active. This theme also addressed language relating to initiating and becoming proactive in personal health. This was reinforced by other members of the forum and ways to be more proactive in personal health were discussed among the group.

Receiving social support and advice are common facets of online support groups (Coulson, 2005; Dennis, 2003; Ussher, Kirsten, Butow, & Sandoval, 2006; Yli-Uotila et al., 2014). For example, Yli-Uotila et al. (2014) surveyed people diagnosed with cancer, mostly breast (42%), to identify how they defined social support and what kinds of support they received from online support groups. The participants defined online social support as empowering and making life easier. They also described how engaging with

each other online provided supportive interactions. This is similar to the analysis of the present study, which identified that members shared support or encouragement with each other when talking about exercise. The members of this forum were supportive of each other's quest to become or maintain an active lifestyle and supported seeking information from each other and healthcare professionals about how best to achieve this goal. It can be suggested then, that bowel cancer patients are interested in exercise and would benefit from discussing this with their cancer care team.

Social support was reported to be an important feature of online support communities (Armstrong & Powell, 2009). In the online community of this current study, social support was identified as part of the theme, *levels of encouragement*. This theme encompassed the predominantly supportive words and phrases that members shared with those who were struggling to stay active or start a more active lifestyle. Supportive words and phrases were identified in a similar study as an important source of motivation for participation in exercise for cancer survivors (Hennessy, Stevinson, & Fox, 2005). It seemed, for the cancer survivor, that the encouragement of fellow survivors played a large role in influencing the activity levels of each other. This was important because it established a source of motivation people with cancer utilised when establishing new or maintaining an active life post diagnosis. In regards to exercise, supportive words from peers appeared to be influential.

However, some of the encouragement posts were perceived as disrespectful by other members and revealed a different side of the support group. Traditionally, support groups are viewed as a place where one can feel comfortable voicing their concerns, opinions, and receive emotional support (Chung, 2014). However, it has also been suggested that the online platform may enable cyberbullying and aggression (Runions & Bak, 2015). Within this form, the traditional sense of comfort had been breached and members of the online community appeared to defend themselves or their choices. Here, some members felt a separation between encouragement and meanness had been established. The individual responsible for the offensive posts had breached the social norms of traditional support and changed the social dynamic of the community. This change influenced future discussions of exercise within the forum. Members who were offended left the online community and forum members who did not find the posts to be

disrespectful were ostracised from the community, which resulted in the discussions about exercise becoming less common and more carefully worded.

The two themes described above differed from each other because the language used and communication style in the theme, *levels of encouragement*, was concerned more with the individual. *Responsibility to oneself and others to be active* adopted inclusive language such as “let’s” and “we” where *levels of encouragement* was directed specifically to the forum member with words including “you” and “you’re”. *Responsibility to oneself and others to be active* demonstrated community support of the community while *levels of encouragement* demonstrated community support of the person. The two themes demonstrated two different ways bowel cancer patients exchanged words of support relating to exercise and physical activity online. Members of the forum may show support in two different ways depending on the context of the post. For example, when one member expressed doubt in their ability to maintain or start a more physically active lifestyle, words of encouragement began to appear from other members. On the other hand, *responsibility to oneself and others to be active* identified statements and phrases associated with declarations made by the self to be more active. Such statements can lead to feelings of empowerment for the online cancer support group member (Barak, Boniel-Nissim, & Suler, 2008) and influence the member’s identity.

People tried to maintain their pre-illness identity by continuing to participate in pre-illness activities (Bury, 2001). One way some members of this online forum did that was by continuing to exercise. Exercise provides a route towards normalcy (Hennessy et al., 2005), while sharing the illness experience online may preserve identity (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005). The value of maintaining their pre-illness selves was made clear with statements about who they are and how not being able to exercise had had a negative effect on their psychological well-being. This indicated the importance of exercise for people with bowel cancer who were active prior to diagnosis. This is important when considering the population of active people with bowel cancer in Australia is less than their non-cancer peers (Eakin et al., 2007).

However, exercise and physical activity had many different meanings to members of this forum. This was identified by the *calibre of exercise* theme. While discussing

exercise, which had no clear and uniform meaning for all forum members, within an online environment where non-verbal cues and tone of voice are absent, negative emotions and animosity did arise from time to time between members of the forum. The scope of what activities defined exercise was a source of conjecture within the online forum, suggesting that more research is needed to further educate bowel cancer patients on what constitutes exercise and physical activity.

The varied opinions of the members on what activities were considered exercise had implications for whether or not other members engaged in physical activity or contemplated engaging. Understanding that all forms of physical activity, regardless of frequency or intensity, helps and some activity is better than being completely inactive would encourage the discouraged to participate at the lowest level, which could lead to greater future involvement. Some members of the forum were more prepared than others to participate in exercise and understood that even small bouts of exercise are beneficial. These revelations will influence the motivation required to initiate and sustain a more active lifestyle.

It is clear that many members of this forum were in different stages of preparedness in regards to changing their physical activity behaviour and were expressing these desires to other members of the group. To foster an increase in the readiness to participate in exercise, requires believing that a change in behaviour will have a positive outcome (Cooper, 2012). Therefore, members of this asynchronous online forum who expressed a desire to change, believed that exercise or physical activity would have positive outcomes for them. It can be suggested they were in the beginning stages of believing exercise would benefit their survivorship or recovery, meaning exercise was becoming increasingly important and they may have benefited further by receiving more information.

Other members of the forum expressed not being ready to participate in exercise or feelings of helplessness about adopting physical activity or exercise. These expressions were identified as part of the *degree of readiness to participate in exercise or physical activity* theme. Helplessness is reported to be a coping style seen across all cancer types (Geyer, Koch-Giesselmann, & Noeres, 2015; Nordin & Glimelius, 1998;

Petticrew, Bell, & Hunter, 2002; Shimizu et al., 2015). The feeling of helplessness has roots in the history of the disease as it was, and still is, thought that the lifestyle chosen by people is primarily responsible for a cancer diagnosis (Sontag, 1979). While a person's lifestyle, including a lack of physical activity, may have increased the risk of developing bowel cancer, it is certainly not guaranteed that living a healthy lifestyle will result in a cancer-free existence. However, it is this traditional and often highlighted view that negatively affects people diagnosed with bowel cancer who maintained a healthy lifestyle prior to the diagnosis.

This analysis also identified negative outcomes associated with receiving unsolicited exercise advice or comments supporting exercise. For instance, as it is common for members of online support groups to compare their situations to those of similar others (Armstrong & Powell, 2009), being unable to participate in exercise or physical activity led to conflict within the group. This may significantly impact the emotional well-being and confidence of those who cannot perform comparable activities to their peers. It is perhaps the judgement placed upon their character by their peers that ignites such passionate contempt for unsolicited advice to exercise. Additionally, these outcomes may reduce participation in the online community because positive support from within the online community motivates community participation (Turner et al., 2001). This may also have the potential to delay the readiness of members to participate in physical activities because they lack the motivation required to do so.

The influence of one's character on disease has been previously reported. Cancer diagnosed based on certain 'character flaws' has been the traditional view as to why some people become ill while others do not. This character flaw was recognised as 'characterological resignation' and is defined as giving in to the disease (Sontag, 1979). This way of thinking may be the reason why there was such a backlash of anger by those who believed that their character was being questioned by other members of the forum. It was as though "Fatal illness has always been viewed as a test of moral character." Sontag (1979) pg. 41).

Negative attitudes about receiving an exercise recommendation have been previously reported by cancer patients (Ungar, Sieverding, Ulrich, & Wiskemann, 2015).

In their report, cancer patients indicated that exercise made them too tired, exhausted, or they did not have enough time to complete the recommended amount of activity per week. As mentioned in Chapter One, completing 60 minutes of exercise on most days of the week is the recommended amount of exercise and provides many physical and psychosocial benefits. However, suggesting this many minutes of exercise per week to an inactive cancer patient, in particular for those individuals undergoing treatments including chemotherapy or radiation therapy, may be too daunting a task to complete. This was demonstrated by several patients exclaiming 150 minutes a week of exercise, which the authors informed the participants was the recommended amount of physical activity, was too much (Ungar et al., 2015). Less negative feelings might occur if the 150 minutes was replaced with a recommendation using less direct language. Patients might agree to a recommendation to exercise by way of less direct or softer language e.g. to increase their levels of physical activity by five minutes per day, as it may appear more achievable and are therefore more likely to adopt it. Future research should investigate different terms and phrases used during physical activity recommendations to measure feasibility and effectiveness.

Some limitations exist that relate to this study. First, descriptions of participant characteristics were not available due to the source of data. Accessing participant characteristics from archived data would breach ethics as was discussed previously. However, with the age of 70 as the median age of diagnosis of bowel cancer (Brenner et al., 2014), and being older negatively associated with Internet use (Girault et al., 2015), it is possible that the older bowel cancer survivors were underrepresented in this current analysis. Secondly, as it has been reported that some Puerto Rican breast cancer survivors preferred to not utilise the internet for seeking information on physical activity (Trevino et al., 2012), the findings of this current study cannot be generalised across all cultural backgrounds. It is possible that other cultures may pursue information from other offline sources, which was not accounted for in this current study. Thirdly, not all bowel cancer discussion forums serve the same purpose. An evaluation of a different online bowel disease support community reported threads were initiated by asking questions as a way to initiate conversations (Gill & Whisnat, 2012). Although this was similar to the online support community analysed in this study, there were several

introduction posts in this study where a member would introduce themselves to the group along with an excerpt about who they were, what their diagnosis was, and any therapies they were currently using or thinking about using. Therefore, the themes discussed in this research may only be applicable to the bowel cancer online support community assessed in the study. While a limitation, these themes are apparent in the threads and speak to the ways some bowel cancer patients discussed exercise and physical activity among themselves in the online medium. They, therefore, can still inform healthcare professionals about the way exercise is considered among some bowel cancer patients and can help inform future physical activity counselling practices and survivorship guidelines. Additionally, this analysis cannot be generalised to individuals with other bowel diseases, such as people with IBD. However, this limitation will be addressed in Chapter Five.

Turner, Grube and Meyers (2001) reported a correlation between time spent reading postings in online cancer communities and shallow traditional face-to-face partner support. It could, therefore, be speculated that bowel cancer survivors with limited local support will spend more time reading the content of online forums and more likely to post. However, this may not always be the case, with Turner et al. (2001) finding no significant interaction between the depth of face-to-face support or the depth of online support and posting frequency. The nature of this current analysis was to review bowel cancer patients' discussions of exercise and/or physical activity and, therefore, particularly passionate members of the group may have increased the likelihood of introducing user frequency bias simply by being more communicative than other members about the topic. This highlights the passion some bowel cancer survivors have in relation to exercise and physical activity and the important role exercise played in their survivorship plan.

In conclusion, this study adds to the body of knowledge surrounding the ways in which bowel cancer patients discuss exercise online. Attention is drawn to the value that bowel cancer patients place on exercise in their cancer journey as well as the way they are sharing that information with others. It is novel in that it looked at the ways bowel cancer survivors communicated with each other in regards to exercise in the online

context. The results of this research may be utilised to inform healthcare professionals about how their patients are sourcing information related to physical activity and exercise.

4.5.1 Reflexivity

Throughout the data analysis for Chapter Four, I kept a journal where I documented my thoughts and feelings as I progressed through the transcripts. One common theme identified in my reflexivity journal was trust. Although I followed every ethical guideline and had been vigilant in maintaining anonymity, I still felt as though I encroached on a private community. The online community was a public space and the organisation responsible for hosting the online community made it very clear on their web page that information posted to the discussion board was public and could be seen and used by others. Members used the private messaging system that was available to members only to share more personal information because this was seen in some of the posts such as *“she contacted me privately to share this with you”* which speaks to the members’ potential knowledge of the public nature of the discussion board; however, the discussion forum still felt like a private community.

I believe this feeling stems from my own personal experience. When I heard a friend share her bowel cancer story with me, it always felt very personal and I had a sense that for her to share this information with me was difficult for her. I was sixteen at the time and she may have been more uncomfortable talking about her mortality with a teenager than the actual disease itself, but that connection over something personal stuck with me and perhaps I projected that personal connection to the members whose stories I read on the forum and during data analysis. This might be a reason for feeling the way I do. A sense of trust was established when this woman shared her story with me and during this process I struggled with projecting this trust onto members of the online discussion group.

As a result of this personal connection and experience with the disease and my training as an exercise physiologist, I felt strong emotions towards posts and threads that expressed passion and enthusiasm for exercise and physical activity as well as the posts and threads that were less enthusiastic. At these moments it was important for me to set the data analysis aside and move on to other tasks to allow myself time to return to a

more neutral headspace. This was a time where it was important to meet with the supervisory team to discuss emerging themes and have a neutral conversation about what was happening in the forum. Immersing oneself within the data requires consciousness of self-perception and the ability to recognise the personal influence of data analysis.

4.6 Conclusion

In conclusion, the analysis of the public online asynchronous bowel cancer discussion board revealed that many members were uncertain about the definition of exercise, although, their participation in exercise was associated with positivity. Forum members also appeared to be aware of and enjoy the benefits of exercise in their recovery and survivorship. It was also apparent that some members were perturbed by discussions of exercise among the group, with such discussions being perceived as negative and threatening.

The results also highlight some key features about the ways with which bowel cancer survivors and patients discuss exercise among themselves and the perceived role exercise has in their recovery. First, bowel cancer survivors were generally supportive of each other's quest to take ownership of their health and well-being by becoming physically active. They encouraged each other, shared the emotions they experienced while trying to become more active, and encouraged each other to be proactive in their own care. However, the manner in which exercise was discussed also appeared to threaten certain members of the forum. It was the high value placed on exercise by some members of the online community that created conflict. The explanation as to why certain members of the online community were negative about discussing exercise can only be speculated, and is an area for future research. The clinical perspective would benefit from understanding why exercise could be considered negatively by some individuals. One lesson that healthcare professionals may learn from such divergent responses is that the initial discussions about exercise and physical activity need to be conducted carefully. Such discussions may need to include conversations about what constitutes exercise and physical activity so to develop achievable goals agreed upon by the patient and healthcare professional.

Second, exercise played a considerable role in the recovery of many of the forum members. This was demonstrated in their posts about the many benefits they received from being physically active during their journey in addition to the encouragement they gave one another and the faith they expressed in exercise helping them live well. It was demonstrated that exercise played a large role in recovery by the responsibility members of the forum expressed to each other about being proactive in their care and encouraging the search of both traditional and non-traditional resources for more information on this topic. Members of this online community were devoted to promoting exercise to each other by the sharing of their experiences with the online community.

The themes identified by this analysis provide valuable insights into how people with bowel cancer experience exercise in relation to disease, the important role of exercise in survivorship, and the context with which they discuss exercise among themselves. This information is important to discussions with healthcare professionals about the role that exercise may play in bowel cancer survivorship and how the patients' perceptions and previously held beliefs may influence their future exercise and physical activity behaviour. Such insight may also influence future exercise and physical activity intervention research in terms of communication styles and techniques of physical activity counselling. The next chapter introduces the second study of this thesis, which explores how people with other bowel diseases, including bowel cancer, experience physical activity and the discussions about exercise they had with their healthcare professionals.

Chapter 5

Study two: Exploring the patient experience of physical activity counselling

5.1 Introduction

The previous chapter explored how people with bowel cancer discussed exercise on a public online bowel cancer forum. An inductive thematic analysis (ITA) of the data revealed that exercise played a fundamental role in the lives of people with bowel cancer. This was explained through themes that defined the purpose of exercise and explored how this was discussed in the online context. Identified within these themes was the value that people with bowel cancer placed on the spiritual, physical, and medical benefits of exercise and the role it served in regards to their treatment, recovery, and survivorship. Findings from the previous chapter also demonstrated that people with bowel cancer might require particular attention during physical activity counselling due to perceptions and previously held beliefs regarding exercise.

The previous chapter also identified how those with bowel cancer, a type of bowel disease, discussed exercise with each other via an online forum. In addition to investigating the role of exercise for people with bowel disease, this thesis explores the experience of physical activity counselling that may occur. This, therefore, demands a phenomenological approach as an experience examined through a phenomenological lens can capture a genuine understanding of a person's life world (Moran, 1999).

As discussed in Chapter Two, this thesis explored how and in what context exercise was considered among people with bowel disease. Hence, it was important to include other bowel diseases in addition to bowel cancer. This chapter will, therefore, investigate the perceived role of exercise for people with bowel cancers including colon, rectum, or inflammatory bowel disease (IBD) and any physical activity counselling that occurred with members of their care teams. This will be achieved through an exploration of the experiences of people with bowel disease. The care teams consisted of doctors, surgeons, and nursing staff. This chapter includes a brief review of the benefits of exercise for people with bowel cancers and individuals with IBD, the lived experience of exercise and physical activity counselling, followed by a description of the methods. A detailed account of the data analysis is presented followed by an in-depth explanation of the results. The results are then considered in relation to the existing literature. A

reflection on the data collection and data analysis phase is discussed followed by the conclusion.

5.2 Background

5.2.1 Exercise and people with bowel disease

The physical and psychosocial challenges faced by individuals with bowel disease including poor quality of life (QOL) (Romberg-Camps et al., 2010; Sánchez-Jiménez et al., 2015) and fatigue (Grimstad et al., 2015; Thong et al., 2013) may contribute to decreased physical activity levels. People with bowel cancers were indicated as 56% more likely to be sedentary than the general public at 12-months post diagnosis (Hawkes et al., 2008) and people with IBD appeared to be active but may not be meeting the standard general guidelines (Mack et al., 2011). However, the prevalence of people with bowel disease exercising was inconsistent within the literature. For example, 82% of bowel cancer survivors met physical activity guidelines of 150 minutes of moderate to vigorous physical activity at 2-5 years and >5 years since diagnosis (Husson et al., 2015). Similarly, people with IBD have been known to participate in exercise activities ranging from 20 minutes up to 100 minutes per week (Chae et al., 2016; DeFilippis et al., 2016). Regardless of these observations, an increase in the level of physical activity for people with bowel disease may help alleviate a variety of physical and psychosocial challenges faced by people with bowel disease and improve their general health and well-being.

As described in detail in Chapter Two, commonly cited benefits of exercise for people with bowel disease included improved psychological health and fitness (Fisher et al., 2016) as well as weight loss, improved energy, and gut motility (Anderson et al., 2010). Exercise was also reported to be enjoyable (44.4%), beneficial (80.5%), and uplifting (61%) in a survey of 158 patients with IBD (Chae et al., 2016). Light physical activity, defined as light housework or slow walking, was associated with benefits in health-related QOL outcomes in bowel cancer survivors, such as lower levels of fatigue and higher social functioning (Van Roekel et al., 2015). Similarly, a review of the effect of physical activity on the QOL of people with IBD reported exercise of low to moderate intensity improved health-related QOL (Packer et al., 2010). Therefore, it would appear

people with bowel disease would benefit from participating in low-to-moderate exercise activities.

It also appears that exercise can improve long-term bowel disease specific outcomes. For example, women with IBD reported utilising exercise to help control some of their symptoms and disease (Sykes et al., 2015) and higher exercise levels were associated with a decrease in developing active IBD (P. D. Jones et al., 2015). Similarly, exercise has also been reported to decrease risk the of bowel cancer recurrence (Denlinger & Engstrom, 2011). A meta-analysis reported greater levels of physical activity were closely associated with bowel cancer-specific and overall survival (Des Guetz et al., 2013). Therefore, people with bowel disease who participated in exercise activities appeared to be living longer and had a better QOL than less active individuals with bowel disease. These findings suggest that exercise is effective in improving QOL and managing bowel disease-specific symptoms. Understanding how people with bowel disease experience exercise may inform how exercise improves their QOL and helps manage symptoms specific to this disease.

5.2.2 Qualitative exploration of the lived experience of exercise

The literature on the experience of exercise for people with bowel disease is limited. Qualitative studies have explored how they experience exercise interventions (Anderson et al., 2010; Knutsen, Quist, Midtgaard, Rorth, & Adamsen, 2006; Spence et al., 2011) and the effects of exercise on cancer treatment-related symptoms such as fatigue (Adamsen et al., 2004). For example, one study investigated the experience of bowel cancer survivors participating in an exercise rehabilitation program following chemotherapy treatment (Spence et al., 2011). A similar study explored the experience of maximum physical capacity testing during chemotherapy treatment and engaging in a 9-week exercise program (Knutsen et al., 2006). The participants from both studies reported physical and psychological benefits from exercising such as improved confidence in their ability to perform daily chores (Spence et al., 2011) and improved confidence in using their bodies in general (Knutsen et al., 2006). The findings from the exercise intervention studies support the benefits of exercise for people with bowel disease. However, as exercise interventions are not currently a part of usual care for

individuals with bowel disease, an exploration of the experience of exercise in relation to everyday life, without organised training sessions, should be explored to gain further insight into how people with bowel disease experience exercise.

In contrast to the bowel cancer literature, exercise has not been the focus of research for people IBD; rather exercise has emerged as a topic by people with IBD as something that offers many benefits. For example, in semi-structured interviews and focus group discussions with people with IBD who had a low QOL based on self-reported measures, exercise was adopted as a behavioural strategy to maintain normalcy (Hall, Rubin, Dougall, Hungin, & Neely, 2005). Exercise was also part of a self-management strategy to sustain control of IBD (Cooper, Collier, James, & Hawkey, 2010). In semi-structured interviews with 24 participants, exercise was defined as providing a sense of control over the body and IBD. For example, participating in exercise activities to maintain fitness was a source of resilience. Exercise was also reported to contribute to allowing people with Crohn's disease to have an increased sense of well-being (Pihl-Lesnovska et al., 2010). This meant that when people with Crohn's disease were able to make conscious lifestyle choices, such as exercising, their sense of well-being improved. Clearly, exercise is important for people with IBD and an analysis of the experience of exercise specifically in this population should occur. As part of this analysis, an exploration of the experience of physical activity counselling can provide a greater understanding of the overall experience of exercise for people with bowel disease.

5.2.3 Exploring physical activity counselling relating to bowel disease

Physical activity counselling with individuals with bowel disease has been explored quantitatively. For example, a sample of cancer survivors, including survivors of bowel cancer, indicated that exercise was discussed in 42.3% of treatment consultations (Lee W Jones & Courneya, 2002). Additionally, 28.4% of survivors reported that the oncologist initiated the exercise discussions and 13.9% reported that they initiated the discussions. This equates to about one-third of the reported physical activity counselling discussions being initiated by survivors, with the other two-thirds introduced by their oncologist (Lee W Jones & Courneya, 2002). Similarly, in a survivor reported survey, healthcare professionals discussed exercise with 59% (n=518/865) of

bowel or lung cancer patients (Kenzik, Pisu, Fouad, & Martin, 2016), although these discussions were more likely to occur if the survivor presented with additional comorbidities such as diabetes. These studies suggest that physical activity counselling with cancer survivors do occur to some extent. However, the context in which they take place and the experiences of these discussions are not known, and information relating to bowel cancer is even more scarce.

Physical activity counselling for people with IBD has not been reported. However, based on the findings from the literature whereby some people with IBD are utilising exercise to help self-manage their disease, exploring physical activity counselling between people with IBD and their healthcare professionals would appear beneficial. Understanding this phenomenon may assist with the quality of care for people with IBD and improve their ability to manage and control their symptoms.

In summary, there appears to be many benefits of exercise for people with bowel disease, yet an understanding of how they experience exercise and physical activity counselling is limited. Therefore, it is important to explore the information about exercise that people with bowel disease are receiving from members of their care teams to gain perspectives on the reality of living with- and receiving care for their disease. This study takes a phenomenological approach to understanding the experience of people with bowel disease in regards to physical activity counselling. Exploring these experiences is central to identifying the role of exercise for people with bowel disease, can assist in the development of physical activity counselling guidelines, and increase awareness of the benefits of exercise.

5.3 Method

5.3.1 Design

Due to the exploratory nature of this investigation, this study employed semi-structured interviews as the data collection method. Semi-structured interviews allowed for refinement of the interview schedule as more data were collected and more interviews were performed. As it was unknown if all participants had discussed exercise with nurses

or other clinicians, the semi-structured interview granted the flexibility required to explore other aspects relating to physical activity counselling that might arise over the course of data collection.

5.3.2 Participants

All 21 participants in this study were diagnosed with either bowel cancer or IBD. Four participants had been diagnosed with IBD, and 17 participants had been diagnosed with bowel cancer. Both groups were in varying stages of the disease. Eight participants were interviewed face-to-face, and 13 participants were interviewed via telephone. The participant chose the preferred method of conducting the interview except where location, such as living overseas, prohibited a face-to-face interview. It was expected that the participant chose the method that would be most comfortable for them.

5.3.2.1 Participant recruitment procedures

Participants were recruited via a number of approaches, with a description of these approaches described in the chronological order in which they were conducted. The first approach included Facebook posts made to the Bowel Cancer Fighters in Australia Facebook group. The Bowel Cancer Fighters in Australia Facebook group was a closed group. Permission was sought from the group Administrator to join the group to post information about the study and the contact details of the researcher. However, members of the group reported that a researcher as a member of their group made them feel uncomfortable. Therefore, the post was deleted and the researcher was removed as a member of the group. The administrator, however, agreed to post on behalf of the investigator. This allowed members of the group potentially interested in participating in this study to acquire more information while at the same time respecting the privacy and wishes of members of the group.

The second method of recruitment was also conducted at a local colorectal surgeon's office. The colorectal surgeon agreed to assist with recruitment through their practice following a meeting with the researcher to discuss the research project aims. On two separate occasions, the investigator visited the colorectal surgeon's practice to discuss this research with interested participants. Following the surgeon's consultation with a patient in a private office, any patient diagnosed as having bowel cancer or IBD

was introduced to the researcher. Following introductions and moving into a private staff breakroom, the researcher informed potential participants about the study. Interested participants were provided with an explanatory information sheet (Appendix B). After an opportunity to ask any questions about the research or request further information, interested participants signed an informed consent form (Appendix C) and the interview process began. After three interviews had been conducted in the office, it was felt by the researcher that the location had an effect on the participants' willingness for full disclosure as it may have appeared that the interview was a reflection of the colorectal surgeon's practice. Therefore, after informed consent was signed by interested participants, a separate meeting was scheduled to conduct the interview, either via telephone or face-to-face at a location of the participant's choosing.

As participant recruitment remained difficult, researchers conducting an exercise study with bowel cancer survivors were approached to assist with recruitment. A flyer (Appendix D) with information about this study was e-mailed to participants of the exercise study. Interested participants then began an e-mail correspondence with the researcher. Some interested participants preferred correspondence via telephone. In this instance, the researcher telephoned interested participants to explain the study further, and an opportunity for the participants to seek clarification was provided. At the participants' discretion, interviews were conducted via telephone or face-to-face at a time and location of their choosing.

Each participant signed an informed consent form prior to their interview. Any person aged 18 and older, who had a previous or current diagnosis of IBD or any cancers of the bowel, and at any stage of their particular disease, was eligible to participate. Participants were excluded if they were unable to be made available for an interview.

5.3.3 Interview development

The interview schedule was informed by phenomenology as discussed in Chapter Three and by the research question; how and in what context is physical activity discussed among people with bowel disease. The findings from Chapter Four, specifically the calibre of exercise and the readiness to participate in physical activity that people were reported to experience also informed the development of the interview. For

example, a notable finding from Chapter Four was that the definition of exercise (or what constituted exercise) varied between members of the online bowel cancer forum. Based on this finding, it became apparent that it was important to determine how each participant of this study defined exercise. This was done to ensure that the interviewer could explore how the participants perceived the benefits of exercise and how this may have been influenced by their exercise definition. This provided a more detailed understanding of physical activity counselling perceived by the participant. Therefore, participants were asked questions such as *“How do you feel the definition of exercise and physical activity differ?”*

Findings from Chapter Four also showed that people with bowel cancer were not always necessarily interested in receiving physical activity advice; therefore, questions such as *“How did this discussion make you feel?”*, and *“What was your perception of your clinician during this discussion?”* encouraged the participant to describe the physical activity counselling experience as an opportunity for the interviewer to gain further insight into the experience of receiving potentially unwanted advice. Finally, participants were asked how they would like to see exercise discussed for people with bowel disease in the future. The final question encouraged the participants to reflect on how they believed their care could have been improved. The interview schedule was modified as more data were collected and analysed. As not all participants discussed exercise with their care team, the semi-structured interview provided the flexibility required to explore how that influenced the participant’s experience. The full interview schedule can be viewed in Appendix E.

5.3.3.1 Pilot interviews

Pilot interviews were conducted with three women. One experienced bowel complications but was not diagnosed as having IBD or bowel cancer. The data collected from her interview was not used in this analysis. One purpose of the pilot interview process was to test the clarity of the questions, in regards to the participant’s understanding of the questions. This was achieved by confirming with the participant following the interview that all questions were clear and understandable. Pilot interviews also provided the interviewer with an opportunity to refine interview skills (Howitt, 2010). This is important to increasing the value of the data within the interview. As a result of

the pilot interviews, it became evident that there were few physical activity counselling discussions occurring among people with bowel disease and nursing staff. Therefore, the question “*Can you tell me about a time you discussed exercise in relation to bowel disease with one of your nurses?*” was reworded to include “*or other clinicians*” to capture more experiences of clinical exercise discussions. Thus, the nurses and other clinicians will be referred to collectively as the care team in the analysis section of this chapter.

5.3.4 Procedure

Participants who chose to be interviewed via telephone were emailed an explanatory information sheet and an informed consent form. Those who wished to participate in a telephone interview signed and returned the informed consent form and a time for the telephone interview was scheduled. Participants had the opportunity to ask for further information about the study during initial expression of interest and prior to recording of the telephone interview. This procedure was repeated with all eight participants interviewed via telephone. The researcher travelled to the homes or the hospital of the participants who wished to be interviewed in person. Upon arriving at the home or the hospital, participants were given the explanatory information sheet to review. Following the review of the explanatory information sheet, participants were offered the opportunity to ask any further questions about the research. Once all queries were addressed, participants were then asked to sign the informed consent form. This procedure was repeated for all 13 participants interviewed face-to-face. Each interview was conducted by the same interviewer.

5.3.4.1 Ethical consideration

This study was approved by the Bond University Human Research Ethics Committee RO- 1961. All the participants were informed that their participation was voluntary and that they could withdraw from the study at any time without having to provide a reason. The participants were informed that the information shared would be confidential. Where extracts were used within this thesis, participants were given a pseudonym to protect the anonymity.

5.3.4.2 Data collection and analysis

Face-to-face interviews were recorded using a handheld digital audio recorder. Interviews conducted via telephone were recorded using TapeACall (TelTech. New Jersey, USA). It is recommended interviews be audio recorded to allow a natural, uninterrupted flow of conversation to occur and reduce potential recall bias (S. E. Kelly, 2012). Professional transcriptionists transcribed the data (Rev.com. San Francisco, USA). To ensure transcription accuracy, audio recordings of the interviews were listened to and transcriptions were read through several times by the researcher. Data were collected until data saturation was considered to occur. This meant that similar occurrences emerged from the data set and new information would not yield any novel themes (Guest, Bunce, & Johnson, 2006). Interviews lasted between 25 minutes to 60 minutes.

Interviews were analysed using inductive thematic analysis as recommended by Braun and Clarke (2006). This involved a line-by-line analysis of the interview transcripts looking for patterns and similarities across the data set and jotting down notes and ideas as analysis progressed. It also involved referring back to the data set, data extracts, and the initial codes being analysed to ensure the coding process was relevant across the data set. The complete details of ITA can be seen in Chapter Three. This section will show how final themes developed from the initial notes relative to this data set (Table 5.1). Further examples are illustrated in Appendix F.

Table 5.1

Example of the development of a final theme

Initial note	Initial code	Provisional theme	Final theme
<i>I started looking</i>			
<i>You seek them out yourself</i>	<i>Proactive in clinical discussions</i>	<i>Exercise helped promote health</i>	<i>Exercise was a catalyst for patients to actively participate in governing personal health</i>
<i>I was the catalyst</i>			
<i>I sought</i>			
<i>Me initiating</i>			

5.4 Results

Twenty-one participants were interviewed. Participant characteristics are outlined in Table 5.2. Four themes were discovered through application of ITA. The first theme, *individual interpretation of the definition of exercise*, described the different ways participants defined exercise for themselves. The second theme, *degree of information about exercise shared during clinical exercise discussions*, revealed that people with bowel disease were receiving insufficient information about exercise from their healthcare team. Theme three, *the assumed positions taken by care teams about exercise affects participants experience*, revealed that patients were sensitive to the attitudes their members of their care team appeared to have towards exercise and this influenced the care team-patient relationship. Finally, the fourth theme, *exercise was a catalyst for patients to actively participate in governing their own health*, encompassed the role of exercise for people with bowel disease

Table 5.2

Participant characteristics

Diagnosis	
IBD	4
Bowel Cancer	17
Gender	
Male	10
Female	11
Age Range	
30-39	3
40-49	6
50-59	8
60-69	3
70-79	1
State/Country	
Queensland	15
New South Wales	2
Tasmania	1
New Zealand	1
Unites States of America	2

5.4.1 Theme one: individual interpretation of the definition of exercise

This theme revealed that the participants had many different personal definitions of exercise. For some, exercise was a planned activity requiring forethought. Janet explained:

How do I define exercise? Exercise is physical activity that I normally wouldn't do in the course of my daily work. I don't really count exercise when I was working and I need to I'm now retired. I don't count exercise as if I had to walk from one place to another at work, that's not exercise for me. Exercise is actually putting on a pair of gym shoes, going for a proper brisk walk, going to the gym, doing Pilates, doing strengthening, muscular skeletal development type things.

Janet. Interview 5. Lines 9-15.

The definition of exercise, according to Janet, involved thinking about the action as exercise. Janet did not consider walking at work to be exercise because walking was defined as being part of work life. However, when the walking was brisk, it was then classified as exercise. Janet separated physical activity performed at work as being work and planned physical activities outside of work as exercise. In Janet's world, exercise and work were two distinct constructs that existed independently of each other. Other participants made similar distinctions. Greg explained:

Greg. Interview 10: I was never a sports person, so I never put any value, I suppose, myself on exercise.

Interviewer: Right, the standard definition of exercise. Which for you is?

Greg: Was physically go to the gym, or that sort of thing, though I always was active... I never lived a sedentary life. I was involved in scouting for 20 odd years, which means you're out and about every weekend, or every second weekend.

Lines 172-178.

For Greg, the definition of exercise involved sports and as he did not enjoy or value sports, he never placed any value on what he considered exercise. Exercise, for him was synonymous with sport and therefore he never saw exercise as being able to offer anything to him. He defined exercise in regards to requiring a designated place or space in which it could occur and drew distinctions between exercise and being active and identified with the latter. He also made sure to clarify that although he did not participate in 'exercise', he was active. He did not want to appear as though he was an inactive person, which suggested that he placed value on being physically active. However, Mike believed being active was exercise. He said:

It's really about just going out, being active, even if that's walking at a higher rate, or a brisk walk is more common for me, what I would consider my own physical activity or exercise.

Mike. Interview 7. Lines 21-23.

Unlike Greg, Mike believed being active was synonymous with exercise. These two participants had different ideas of what it means to exercise and be active. The differing views may have implications for physical activity counselling in regards to the various definitions associated with principal terms relating to movement. For example, suggesting an increase in activity to Mike and Greg may have potentially different outcomes as Greg associated active with daily living while Mike associated active with brisk walking.

For some participants, exercise was defined by the purpose for which it was performed and formed the foundation of the definition. Susan said exercise was:

..., just any movement of your body, whether it's more cardio or more like yoga. Different forms, walking, anything to keep yourself fit, I would say.

Susan. Interview 2. Lines 13-14.

For Susan any activity that resulted in maintaining fitness defined exercise. The definition was an abstract concept where the purpose and outcome was the basis for the definition. The definition of exercise was not explained concerning activities that may be classified as such, but rather by a general idea of the primary purpose of it and the end goal, which was to maintain fitness. This differed from Greg and Janet's perceptions of exercise, where it was defined in regards to specific activities, i.e. go the gym. In Susan's world, exercise was defined in regards to what she considered the purpose of it to be, which was maintaining fitness. Maria also had a similar definition of exercise. She explained:

Because I'm a busy person, I work Monday through Friday and I've got children at home, so to me exercise is if I keep myself healthy and achieve anything above 10,000 steps, and I normally do about 20,000 steps including my daily walk. About 20,000. And that's the only exercise I do.

Maria. Interview 1. Lines 8-11.

These statements demonstrated that these participants described exercise as serving a purpose. Susan and Maria defined it in reference to how it affected the body. The result formed the foundation of their definition.

Overall, these participants felt that exercise could be interpreted to mean different things because each participant had an individual idea of what it meant. The variation in the definition and understanding of the definition may have contributed to the participants' perceptions that a lack of information about exercise was shared during clinical discussions. For the remainder of this chapter the term 'exercise', will refer to the participants' interpretation of the word. This has been done to clearly capture the experience of physical activity counselling as perceived by the participant.

5.4.2 Theme two: degree of information about exercise shared during clinical discussions.

This theme describes the level of physical activity counselling that the participants experienced. This theme identifies that some participants recalled never being counselled about physical activity or exercise, while others shared they did remember some counselling. For example, Greg said:

No. No, there was no this, “Oh look, you should be doing exercises,” or you should be doing this, or should be doing that. I basically got out of the hospital and came home. Then that was it. There were no follow-ups, other than we went to the oncologist then.

Greg. Interview 10. Lines 92-95.

This statement described the dearth of information about exercise received from anyone at the hospital, and as such, contributed to an experience with care that appeared task-oriented and detached from any personal relationships or interaction. Louise shared a similar story:

It would have been good to have some information, more information I guess, from the team. There was mention of it. Mostly it was try to live your life as normally as possible, to my memory of it. That’s the thing they emphasised. When you’re knocked about by the chemotherapy it’s hard to do.

Louise. Interview 8. Lines 175-178.

Louise was told to live her life as “normally as possible” without reference to the fact that she was in the middle of chemotherapy and following that advice appeared difficult and highly unlikely. Furthermore, without the care team recognising the complications that chemotherapy can have, it was not clear to Louise how she was supposed to follow this general advice. Therefore, the advice she received was not about her needs or her

situation at that time. “Normal” appeared as a common construct within physical activity counselling. Sara received similar advice to resume normal activities.

...I think the only exercise that I was ever encouraged to do was right after surgery, like the next day. Other than that there were no discussions as to... It was basically, you'll be back on your feet in X amount of weeks, back to your normal activities, was all I ever got.

Sara. Interview 3. Lines 8-12.

These statements illustrate that participants' experiences of discussions about physical activity or exercise by members of their care team lacked specific information the participants appeared to desire. These statements are suggestive of task-oriented care, in which general advice is recommended with no reference to the fact that people with bowel disease are likely to have a different way of living, and they may need guidance on what to expect at different stages of their treatment or disease and in accepting what that new normal may be. Other examples included:

Last year when I had chemo, my doctor definitely, he said, “Exercise when you can.” Even for when we thought it [cancer] had gone, he was like “Recurrence levels, it's really good to keep exercising.” He did say exercise is good, but he didn't say what to do. There was no direction. It was more general, “exercise.” Do you know what I mean?”

Susan. Interview 2. Lines 109-113.

For Susan, even when her doctor mentioned exercise, she had many unanswered questions in regards to what he meant by exercise. The advice provided to her was not sufficiently detailed about what she should do, and as a result, she was left to determine the meaning of these conversations. This statement suggested limited communication between the doctor and patient in terms of the doctor not ensuring that the patient was confident with the information given following a physical activity counselling discussion.

For some participants, the degree of information was not important, while for others it influenced their experience with care. For example, Bill also dealt with the challenges of chemotherapy, yet had a different experience with physical activity counselling.

In terms of my discussion of exercise, given, that it's now five years since I was diagnosed. I'm trying to recall back. I don't recall ever having a specific discussion with the chemotherapy nurses regarding any form of exercise during or immediately after my chemo. However, because of my wife's background as a nurse, and I've also had a lot of exposure to Camp Quality, which is a camping and sport program for children with cancer, we were aware that chemotherapy could knock you around a bit. We're basically going to take it on a day-to-day basis during my chemo, so we didn't necessarily enquire about exercise, but I know the two particular nurse that looked after us during my course of chemo, if we had any questions at all we could ring them any time and ask them. They never said we couldn't exercise, so we basically worked on the basis that if I was feeling good enough, then we'd give it a crack and see what happened.

Bill. Interview 13. Lines 17-29.

Bill did not discuss physical activity with his nurses. However, the lack of information he received did not hinder his attitude towards exercise, nor did he feel defeated by the lack of information he received. From Bill's experience, a lack of physical activity counselling did not bother him because he knew how difficult it would be to exercise during chemotherapy. In this way, physical activity counselling was not important to his recovery. Additionally, he attempted exercise on his own terms and when he felt capable. One reason the lack of activity counselling did not appear to impact his experience was because he was aware of the side-effects of chemotherapy based on prior knowledge and. therefore, was better able to mentally prepare for that experience. Perhaps, in Louise's case, had she been made aware of how chemotherapy affects a person, the advice to carry

on with life, as usual, may have had a different impact. Similarly, Janet summarised her experience with physical activity counselling:

I probably should tell you, at no stage though... You've only made me think about this now, at no stage did anybody come and see me specifically about exercise to say... In the hospital for example, I did see a physio who just wanted to see that I could actually walk well, but I think... I often get the feeling that's about them covering rear ends in your welfare, if you understand what I'm saying.

Janet. Interview 5. Lines 278-283.

This extract demonstrates the level with which physical activity occurred as perceived by Janet. For her, the physical activity counselling she did receive appeared contrived and insincere. Based on her experience, she indicated that the healthcare professionals in charge of her rehabilitation and recovery were more concerned with protocols and procedures than ensuring the patient received the best care.

Sometimes physical activity counselling encompassed information about movements that should not be performed. For example, Lucy was told what not to do.

My entire experience in most of the times I was hospitalised or in and out of the doctor's office, I don't think anyone except for after I've had major, major bowel surgery where they literally cut me open like a good seven, eight, to ten-inch scar, I don't think that anyone mentioned anything about exercise. I think the only time that they did was to say avoid doing sit-ups or avoid strenuous things or lifting while your bowel incision is healing. That's it. There was never any recommendation for it. There was never any connection or correlation mentioned between your physical well-being and your mental well-being and how exercise reduces stress. None of that, ever.

Lucy. Interview 15. Lines 63-71.

Lucy explained what information about exercise the care team did share; although, this information was based on their assumptions that she would attempt or try to do them, and did not satisfy her needs for information about exercise. She expressed wanting to know more about the benefits of exercise for physical and psychological stress from the care team, but it was never mentioned nor discussed. The care team described some forms of exercise as activities that she should not perform, instead of describing other types of exercise as something that could contribute to a positive mental, physical or spiritual experience for Lucy. The lack of recommendation on the benefits, as well as potential harms of exercise, could create a negative perspective and view towards exercise for people with bowel disease.

Mike also explained that exercise was not promoted as part of the healing or acceptance of living with bowel disease process. Staying active, according to Mike, was not part of learning to live with IBD. He explained:

Because, if you look at things like message boards, or places like online communities, it's usually a sub-thread, it's not a main component alongside nutrition, symptoms, medications, emergencies. It's a thing that comes up on an individual case basis. Particularly by people who are really active, who then have to adjust their whole lives and rebuild, and reorient towards what is it going to take to be a marathoner again if I have IBD? It's not central to how you manage your care. At least in my experience, and I would say that feeling I've had exceptional care.

Mike. Interview 7. Lines 226-232.

Exercise did not appear to be a main component in helping people recover or learn to live with bowel disease. Mike described how exercise was seen as an extra or only relevant to those who wanted to be elite athletes. This rhetoric described exercise as only applicable to trained athletes and dismissed the potential benefits small bouts of exercise could have for less active people with bowel disease. His statement expressed the lack of information shared about the ability of low or moderate intensity/duration exercise to provide benefits. Furthermore, Mike described his care as outstanding, indicating that,

for him, physical activity counselling was not necessarily a priority in regards to what he wanted, or expected, from his care team or was it involved in his own way of dealing with his bowel disease. His attitude towards exercise was quite different to Lucy's, who overtly expressed a desire towards receiving more specific information about exercise for her care. These two opposing views highlighted the individual differences in priorities when it came to being counselled on physical activity. This may have influenced their experience of care. Additionally, the lack of information about exercise shared between participants and the care team seemed to influence participants' attitudes towards exercise. This is the next theme to be discussed here.

5.4.3 Theme three: the assumed positions taken by care teams about exercise affects participants experience

This theme describes the effect of the participants' perceptions of their care teams' attitudes towards exercise. Participants explained how they trusted that their care team had provided them with all the important information about their disease and if exercise had been important, the care team would have mentioned it. When asked if it would have been beneficial to receive information about exercise from the care team, Steve said:

Yeah, if they thought it would've helped me, I mean physically it would have helped me, but they didn't seem to mention it to be honest.

Steve. Interview 11. Lines 94-95.

He explained that because the care team never mentioned exercise, it was not considered important in helping recovery or important to living with bowel disease. However, he believed that exercise would have been physically helpful. Bill felt the same way. He said:

I'm pretty sure that those guys... if there was some sort of evidence that suggested that it would be good for me to exercise during the course of my chemo, then they would have said it. The two nurses that I worked with during chemo were pretty on the ball in terms of the research, and stuff like that. As I said, they were quite

happy to answer any questions and things like that. If the oncologist, or any of the medical research available at the time, had suggested benefit in exercise during chemo, they would have said something to me, and I would have gone and done it. We were trying vitamins we were trying acutheraPy. We tried all sorts of things during my chemo to manage the various symptoms and impacts on my lifestyle. If they said, "Go out and do some exercise," I would have gone and done it.

Bill. Interview 13. Lines 108-120.

Steve and Bill shared a similar sentiment and trusted that the care team had provided them all the information relative to managing symptoms associated with their treatment. Bill expressed a belief that exercise would not have helped manage or alleviate some of the side effects of chemotherapy because the care team did not mention it. Although he did not say what the side effects were, the nurses and oncologist utilised other types of non-traditional therapy including vitamins and acutheraPy to help alleviate the symptoms. It seems that the care team was not opposed to other forms of treatment, yet exercise was never discussed, even though one component of acutheraPy is corrective exercise. This suggests that some form of exercise might have occurred. However, this did not qualify as exercise according to Bill's definition of exercise.

The participants' assumed positions of care team members impacted care team-patient communication. Maria explained below that she didn't discuss exercise with her care team because she felt that they did not feel exercise was important.

Maria. Interview 1: They don't ask me about it [exercise]. They don't... We don't talk about it.

Interviewer: How does that make you feel?

Maria: Well, I've... I don't know. I just feel that because it's not being asked, so it's probably not important to them.

Lines 19-22.

Maria made assumptions about the information that the care team deemed important based on the information shared during clinical discussions. Therefore, she felt uncomfortable discussing exercise because the care team did not initiate an exercise discussion. This might have influenced the care team-patient relationship because a person living with bowel disease may not want to feel that the care team does not approve of exercising.

Some participants described how the perception of their care team's attitude towards exercise influenced the care team-patient relationship. Lucy explained how her care team viewed exercise and how this impacted her experience. She said:

When I say that they're a little irresponsible, it's because truly they're putting absolute poison into people's bodies instead of using actual healing methods. I mean, in eastern cultures and civilisations, they go about things totally differently. Here, their educations are funded by pharmaceutical companies, which they're taught to pump drugs in us. It's just not right. It's not very cool.

Lucy. Interview 15. Lines 126-130.

Lucy's statement described how the care team seemed more interested in prescribing medication rather than suggesting alternative methods or supplementing traditional western medicine with alternative treatments. This was, according to her, irresponsible of the care team. This statement described a sense of mistrust in the medical system because of a disregard for alternative or complementary therapies. For Grace, this idea of irresponsibility influenced her approach towards exercise.

Grace. Interview 4: No, I just didn't think that, especially my oncologist, he was very quite... He was a lovely man and was fantastic, but he didn't believe that, number one, I would live for very long and he didn't think... I don't think he saw my treatment as a holistic approach. It was just more about keeping me alive on chemotherapy.

Interviewer: How did that make you feel? How did that influence your approach to exercise?

Grace: It made me more determined to prove him wrong, because I wasn't going to go down that road. It just wasn't an option for me. Basically, I didn't listen to him and I just followed my instincts... I didn't feel like he was doing everything he could to help me, I guess. When he kept saying that...Sorry. He kept saying that I wouldn't be living for very long, so this is [exercise] the only thing I could do.

Lines 52-63.

Grace explained feeling upset about the care she received from her oncologist. For her, not discussing exercise meant that the oncologist was not doing everything to help her, meaning that Grace relied on personal instincts to aid in the treatment process.

Furthermore, she reported not listening to the oncologist, which suggested that she had a lack of trust that affected their relationship. This statement demonstrated the power and value that exercise could have for people with bowel disease and how, when the value placed on exercise was not perceived to be equal between care team and patient, the experience of being ill was negatively influenced. She also recounts using exercise to prove the oncologist wrong in suggesting she was not going to live for very long and therefore, participating in exercise, for her was a way to control her own fate. She took control of her own care because she was not receiving the information or care she needed from her care team. This was observed across the data set and is the final theme of this analysis.

5.4.4 Theme four: exercise was a catalyst for participants to actively participate in governing their personal health

This theme addressed the value of exercise for people with bowel disease. It demonstrated that participants were proactive and took responsibility for their health. This theme illustrated the mental health benefits of exercise that people with bowel disease discussed. It also encompassed participants' positive experiences with exercise and how physical activity improved their mental outlook by promoting a mind and body consciousness. Betty described exercise as:

It brought inner peace. It brought stillness. It relieved mind chatter. It helped me sleep. It helps me sleep. I don't sleep well often because of medications and just the illness. You're up and down emptying the bag too depending on what you've eaten. Since I've had the bag I've never slept a full night because naturally not everyone gets through the whole night without emptying.

Betty. Interview 9. Lines 127-131.

Exercise, for Betty, had helped relieve her of some of the difficulties associated with living with bowel disease. Betty had a permanent ostomy, and while this provided her with many obstacles, she utilised exercise to make those barriers less impactful, such as being active to help her sleep because she knew that her sleep quality was inadequate due to her ostomy bag. Exercise had a therapeutic effect on her and provided a reprieve from the consequences of bowel disease. Other participants reported similar benefits. Louise said:

Mentally it clears your head, blows the cobwebs away, let's your thoughts come through. You plan the day, whatever, you know, when you're doing especially the walking. When you're at water aerobics you've got to concentrate on what you're doing there so it doesn't quite clear your mind the same way though there are some exercises in the start and the end to build up and that, and the cool down at the end. It clears your head.

Louise. Interview 8. Lines 98-103.

Walking provided an opportunity for Louise to navigate her thoughts. On the other hand, water aerobics demanded a degree of cognition that provided her with few opportunities to think about much else. Louise described exercise as an external focus with which she achieved some mental clarity because it caused her to think outside of herself.

Participants frequently mentioned exercise as providing them with an opportunity to focus on external aspects of their lives. Furthermore, exercise was associated with clearing the mind. Susan explained her experience:

It's not just a stroll down the street for ten minutes. I will do a walk, but, yeah, things definitely, yeah, clearing the head, and just a bit of fresh air, and helps if you're feeling a bit sick and a bit seedy, a bit nauseous. Then with Pilates, I find because you have to concentrate on what you're doing with your body, it's really good. When you're really focused on it, it does take you out of your head, and you're focusing on what you're doing.

Susan. Interview 2. Lines 59-54.

Focusing on movement was one way this participant found exercise to be beneficial. Walking helped Susan overcome some of the consequences of living with bowel disease, such as nausea. She also explained how Pilates had helped take her mind away from the symptoms of bowel disease and toward connecting with the body. The role of exercise for her was a type of treatment or remedy that helped alleviate some of the symptoms by allowing her an opportunity to engage with the body and concentrate on its motion.

Some participants took control by seeking out exercise information and initiating physical activity counselling with members of their care team. Participants described how exercise helped them to become a facilitator in controlling their health by asking the nurses specifically, about exercise. In one instance:

I was just going to say, and then this time... The chemo nurses, I think I said once, "Can I do blah, blah, blah?" They're like, "Yeah, you can do whatever exercise you can manage, and whatever feels good," but once again, that was probably me initiating the conversation, and there was no set direction. This year, I'm at a different hospital. Yeah, once again, there's no specific direction, or even saying, "You should be doing X, Y, Z." There's none of that.

Jill. Interview 6. Lines 118-123.

Jill described one context in which exercise was discussed. In this regard, she initiated the exercise discussion by asking nurses about appropriate activities. This statement suggests that Jill had initiated many previous exercise discussions during her illness experience and was still not receiving the information she wanted. Jill wanted an exercise script or an activity plan with a list of activities in which she could participate. As she was not receiving this information as part of her care, she took it upon herself to ask her nurses about what activities were appropriate for her. Another example of proactive searching to become more informed about the possible benefits of healthy behaviours:

I remember when I first got sick, I started looking up, trying to look up, diet and exercise online, and I got really, really stropky about it, because it's all about looks. I was like, what is going on here? Where are these people priorities, come on!

Tracy. Interview 14. Lines 355-357.

Tracy recounted an experience she had when searching for information about how healthy behaviours such as exercise and healthy eating could help her manage her disease. What she found on the Internet upset her because she believed it fostered the wrong agenda on people with bowel disease. She viewed exercise as offering more than just aesthetics and was not interested in that part of it. She could not understand how people with bowel disease would be interested in exercise for looks instead of health.

For people with bowel disease, the ability of exercise to alleviate many of the negative consequences of their condition and treatments, and, therefore enhance their

perceptions of their overall health and QOL was important. People with bowel disease were encouraged to seek out information based on their attachment to those pleasant feelings and mental benefits. Clearly, exercise provided people with bowel disease with a sense of calmness and peace.

5.5 Discussion

An ITA of interviews with people living with bowel disease yielded four themes. *Individual interpretation of the definition of exercise*, revealed that there was no standard when it comes to the definition of exercise as each participant defined it differently. *Degree of information about exercise shared during clinical discussions* acknowledged that the participants reported that the care team did not sufficiently discuss exercise and its potential benefits with them. The third theme, *the assumed positions taken by care team members about exercise affects patients experience*, explained how the perception of the care teams' attitudes toward exercise influenced the participant's experience of their care. The final theme, *exercise was a catalyst for participants to actively participate in governing personal health*, demonstrated that participants were proactive in seeking information related to exercise and participated in exercise as a way of managing their own care.

As expected, the definition of exercise varied across all participants. Definitions ranged from vague descriptions including general movement to more specific actions such as putting on specific gym clothing. However, the participants also described exercise without reference to bowel disease. In this study, they referred to engaging in walking, Pilates, rowing, and cycling activities as some of the things they did to maintain their health. These findings are similar to a study by DeFilippis et al. (2016) which reported that people with IBD participated in walking, running, weightlifting, cycling, and yoga. Therefore, it appears people with bowel disease do not allow the disease to confine them to a particular sport or activity and can participate in a range of activities.

The findings also suggest that people living with bowel disease were not satisfied with the current physical activity counselling they received from their care team. All participants interviewed described receiving little or no information about exercise.

When participants reported receiving such information, they described it as vague, as it did not include specific information such as how frequent or what modes of activities were appropriate. Similar findings showed that people diagnosed with various cancers reported their healthcare professionals to lack communication skills during consultations (Steinsbekk & Launso, 2005). Furthermore, a study on patients' experiences of communicating with nurses on the ward revealed that lack of communication was commonly mentioned (McCabe, 2004), and if the content of discussions was vague and unclear, patients felt vulnerable about the level of their care (Bertero, Eriksson, & Ek, 1996). Such results suggest that patients want information and knowledge in order to participate in their own care (Bertero et al., 1996). Therefore, not supplying people with bowel disease with appropriately detailed information about exercise may be discouraging them from participating in their own care.

The benefits of exercise for people with bowel disease have been reported previously; however, the finding that exercise played a potential role in influencing participants' perceived quality of care provides new information about the role of exercise in this population. Theme three, *the assumed positions taken by care teams about exercise affects participants experience*, described an outcome, such as quality of care received or patient satisfaction that resulted from these perceptions. For example, some participants in this study shared that the care team would have suggested exercise had it been important to recovery. This suggests that participants trusted their care team because trust was gained when patients believed their nurses were clinically knowledgeable (Fosbinder, 1994; Tay, Hegney, & Ang, 2011; Thorsteinsson, 2002). Furthermore, trust was a significant contributing factor to patient satisfaction with care and fostering a valuable doctor-patient relationship (Shan et al., 2016). It can be speculated then that the participants who reported their care team engaging in physical activity counselling also had a favourable care team-patient relationship.

However, the data also suggested that participants experienced disappointment and dissatisfaction in the care they received because of the lack of physical activity counselling during care. Participants evaluated the quality of care they received based on clinical competence, and when clinical competence of healthcare professionals was perceived to be low, the experience of care was reported to be unsatisfactory (Shan et al.,

2016) and stressful (Bertero et al., 1996; Thorsteinsson, 2002). Similar findings appeared in the current study where the participants expressed some dissatisfaction with the quality of care they received as a result of exercise not being a part of such discussions with their care team. These findings suggest that the participant's perception of the care team's attitude toward exercise influenced the quality of care perceived by the participant. Furthermore, the care team-patient relationship may have been negatively affected because information sharing was important to establishing a positive rapport (McWilliam et al., 2000).

Other aspects of discussions may be affected by the perception of care team attitudes. For example, the information shared during physical activity counselling may be influenced by patients' perceptions. It has been previously noted that patients adapt to what they believe the care teams want to discuss during the consultation (Arora, Jensen, Sulayman, Hamilton, & Potosky, 2013; Steinsbekk & Launso, 2005). Steinsbekk and Launso (2005) argued that this gave the power of the consultation to the care teams and any opinions the patients may have had in regards to the importance to their own care, may have been dismissed by the patients themselves because of their perception of what their healthcare teams deemed important. This was illustrated in the interviews as some of the participants did not raise questions regarding physical activity as they perceived that members of their care team were not interested in discussing it with them.

The relative lack of information about exercise shared during clinical discussions led many participants to seek out information from other sources. This was captured by theme four: *exercise was a catalyst for patients to actively participate in governing personal health*. The theme encapsulated the role of exercise for people with bowel disease because it identified that exercise was the facilitator for patients to initiate clinical exercise discussions with their care team. Participants actively participated in governing personal health when they initiated clinical exercise discussions. The idea of exercise, or actually exercising, encouraged participants to control the information they received from their care team. Exercise encouraged participants to engage in decisions about their recovery or how to manage their disease. It was also a means for controlling symptoms. This is similar to previous reports where exercise contributed to disease and symptom management for people with IBD (Bilski et al., 2014; Klare et al., 2015; Shephard, 2016).

The data also identified that exercise was a catalyst in helping people with bowel disease improve physically and psychologically. The participants illustrated the ways in which exercise enhanced their relationship with their bodies and their mind by promoting an improved mind and body consciousness. Similarly, a phenomenological exploration of the experience of exercise for female cancer survivors identified that exercise provided the opportunity to move forward, both physically and psychologically (Hennessy et al., 2005). As the information surrounding exercise in regards to the qualitative assessment of the exercise experience for people with bowel disease remains scarce, the findings of this current analysis add further evidence to the benefits of exercise for people with bowel disease.

Some limitations of this study exist. First, the experiences of the participants in this study may not be representative of all experiences people with bowel disease have had discussing exercise with their care teams. As the nature of this research was to explore the experience of exercise and physical activity counselling and participation in this study was voluntary, it can be speculated that only people with a genuine interest in exercise participated in this current study. Therefore, the experiences of people uninterested in exercise or discussing exercise with care teams may not be represented in this data set. Second, this study relied on participants' memory of the discussions they have had with their care team. It is possible that the participants interviewed in this study did receive information about exercise yet did not remember the nature of these conversations. However, because the participants discussed engaging in physical activities and exercise and the many benefits they encountered as a result of doing so, it can be speculated that if participants had received information regarding exercise, it would have been recalled. Future studies whereby consultations among care team members and patients are recorded and analysed for physical activity content could address these limitations. This approach would provide further insight into counselling practices and the interactions that occur as a result of these practices.

5.5.1 Reflexivity

The lack of information patients reported receiving from their care team was a common theme within the data set. During the development of provisional themes, I struggled with trying to create a provisional theme for the lack of information received during clinical exercise discussions that met the recommendations of Braun and Clarke (2006) yet did not have negative undertones. I believe this struggle was a result of not wanting to illustrate the care team negatively. I felt it was important that this analysis was not a report of the failings of the system because that was not the purpose of this enquiry. This emphasised the importance of discussing the data analysis process with the supervisory team. It was within these discussions, I was reminded of the research question, the experience of physical activity counselling, and the experience of physical activity counselling could not be maximally explored without addressing other aspects revealed in the data.

The extracts in the transcripts that told of the benefits of exercise also drew my attention. I enjoyed reading about how exercise had provided a positive influence for people with bowel disease. I believe I was pulled to these particular stories for two reasons. One, as an exercise physiologist, I am always inspired by stories of how exercise provides people with greater strength and endurance because I understand, at a physiological level, the changes that occurred to help this person feel this way. Secondly, I watched my father live it. My father was diagnosed with Stage IV Melanoma. He had all the lymph nodes in his underarms removed and death became a very real outcome. I have vivid memories of him sitting at the computer for hours researching all of his treatment options and coming to the conclusion that in order to beat his disease, he was going to have to make his body stronger. He made a conscious decision to be more active and do more than he used to, to help his body fight his cancer. I was drawn to the extracts about the benefits because it felt as though I was reading about my father and what sort of things he might say, feel, and experience.

To address this potential bias, I made meticulous notes evaluating the participants' descriptions of the benefits they received from being physically active. These notes provided me with the foundation on which to build themes that related to the participants

own descriptions while addressing my own preconceived notions of how exercise provides benefits to people with disease. I also drew from another experience I had with a friend, who died from bowel cancer despite living an active lifestyle. This helped me challenge my predetermined ideas about the value of exercise in improving survivorship to life-threatening disease. I believe my personal experience with my father improved these findings because I felt I was able to align myself within the worlds of the participants.

5.6 Conclusion

The results of this study stressed the importance of care teams meeting the information needs of their patients. The analysis of this data indicated that care team-patient relationships are influenced by the physical activity counselling practices of care team members, and that a lack of physical activity counselling results in the information needs of people with bowel disease not being fully met. The lack of information about exercise shared by the care team led many of the participants in this study to reflect negatively on their experiences.

Although the literature on the patient experience of health communication in regards to exercise counselling is limited (Tay et al., 2011), the findings of this study can provide valuable insight into how health communication, specifically communication regarding exercise, can influence the clinical experience of people with bowel disease. This information is important to creating an exceptional quality of care for people with bowel diseases. Additionally, nurses and other clinicians may utilise these findings to improve the clinical experiences of their patients with bowel disease through modification of information shared during clinical discussions.

The results of this chapter are similar to the results from Chapter Four in regards to how people with bowel disease expressed their views on how they believed exercise was beneficial. The findings also highlighted the importance that people with bowel disease placed on exercise to help them alleviate many of the side effects and symptoms associated with living with such disease. The findings from this study also concluded that physical activity counselling did not appear to be a standard part of care, and even

when exercise was discussed, the detail provided was too general and did not fully meet the patients' needs. To further this understanding, the next chapter and final study of this thesis will explore the counselling of physical activity from the point of view of the nurses who care for people with bowel disease.

Chapter 6

Study three: The nurses' perceptions and practices of physical activity counselling

6.1 Introduction

The findings from Chapter Four demonstrated that exercise has an important role in recovery and survivorship of people with bowel cancer and that special consideration may be required during physical activity counselling with individuals with bowel cancer. The results of Chapter Five added to the knowledge surrounding the benefits of exercise for people with bowel disease, including those with inflammatory bowel disease (IBD). These findings also revealed that people with bowel cancer and IBD remembered receiving limited information about exercise from members of their care team. Themes that emerged from the bowel disease patients via an inductive thematic analysis (ITA) of the transcripts included: *individual interpretation of the definition of exercise* and *the assumed positions taken by care teams about exercise affects participants' experience*. These themes demonstrated that people with bowel disease were sensitive to the information about exercise shared during clinical discussions. These findings also showed that the exchange of information about exercise had the potential to influence relationships between care team members and people with bowel disease.

The findings from both chapters concluded that while people with bowel disease value exercise as part of their lives, the information provided by their healthcare professionals did not meet their needs. This chapter documents the final qualitative study of this thesis and investigates physical activity counselling for people with bowel disease from the perspectives of nurses. Although the previous chapter reported that people with bowel disease received limited information about exercise from any member of their care team, nurses were chosen as the participants for this study because people with bowel disease have previously identified that nurses were the preferred source of health-related information (James-Martin et al., 2014; Lesnovska et al., 2014). Additionally, nurses were indicated as providing physical activity counselling to their patients more frequently than other healthcare professionals including GPs and oncologists (Douglas et al., 2006; Karvinen et al., 2012) and identified themselves as the primary providers of physical activity advice (Keogh, Puhlinger, et al., 2017). Therefore, exploring physical activity counselling from the perspective of nurses may add more insight into how and in what context exercise is discussed among people with bowel disease.

This chapter reviews the background on physical activity counselling for people with bowel cancer, followed by a discussion of counselling for people with IBD, and then explores physical activity counselling from a nursing perspective. Following the review, the method and interview development are documented. A description of the interview development and a detailed account of the results analysed through ITA is presented, followed by the results which are discussed in relation to the current literature. Finally, the chapter ends with a reflection on the data collection and analysis phase, followed by the conclusion.

6.2 Background

6.2.1 The role of nurses in IBD care

Nurses appear to play a pivotal role in caring for people with IBD. For example, nurse-led counselling services for individuals with IBD have been identified to be beneficial in regards to improving measures of quality of life (QOL) (G. D. Smith et al., 2002). In a randomised trial involving 50 outpatients with IBD, physical and psychological well-being improved over six months compared to routine clinical follow-up as a result of nurse-led counselling. However, at 12-month follow-up, the scores were no longer significant. The authors argued that the lack of significance at 12-months was a result of an increase in the well-being scores of the routine care group. It was suggested that greater attention from nurses and research staff as a result of occupational contact to collect data information, might have contributed to the increase. Such a finding may imply that continual contact with nurses is beneficial for IBD management and improved QOL.

Nurses are also identified as important IBD educators, as IBD education delivered by nurses has been shown to significantly improve patient satisfaction (Waters, Jensen, & Fedorak, 2005). Forty-five patients with IBD randomised to an education program and standard care group reported greater satisfaction with understanding their disease, information needs, and general satisfaction, compared to the control group that included informal education during clinic visits. The control group also increased their scores, which is commensurate with the findings of Smith et al. (2002). The crossover

demonstrated by these two studies may indicate that more nursing attention, regardless of the intervention structure and content, can provide positive influences to people with IBD.

Research suggests that nurses are essential to IBD disease management. A survey of 135 healthcare professionals, including 68 gastroenterologist specialists, 46 nurses, 11 psychologists, five dieticians, three surgeons, one psychiatrist, and one physiotherapist, indicated that nurses should play an important role in IBD patient services (Mikocka-Walus et al., 2014). The surveyed healthcare professionals determined that nurses should have a central operational role in providing services to people with IBD. With this in mind, it is important to explore physical activity counselling following treatment from the perspective of nurses. Nurses on the surgical ward are usually the first healthcare providers that people with bowel disease would communicate with in regards to recovery. Therefore, this places the nurse in an ideal position to provide physical activity counselling, as a means of assisting their patients in returning to the preoperative level of functioning, health and well-being.

6.2.2 The role of nurses in bowel cancer care

Literature regarding the role of nurses in caring for people with bowel cancer is limited. Some evidence suggests that nurses appeared to play a part in the management of bowel cancer through follow-up care and nurse-led interventions, which seemed to improve symptoms of cancer-related treatment. A randomised clinical trial conducted over a 20-week period indicated that a nurse-led tailored intervention program for breast, lung, or bowel cancer patients undergoing chemotherapy produced significant improvements in physical functioning at the conclusion of the trial (Given et al., 2002). Cancer survivors in the intervention group also had fewer symptoms per week than the usual care group. These improvements in bowel cancer patients suggest that nurses are central to disease management and that their involvement could have a positive influence on the lives of people with bowel cancer. A study that followed 60 bowel cancer patients over a period of one year reported similar findings (Knowles et al., 2007). Patients were followed up by nurses 2-3 weeks post-operation and then again at four, eight, and 12 months. Follow-up appointments consisted of symptom assessments, routine blood test, and clinical rectal examinations. At the 12-month follow-up, patients reported significant

improvements in perceived global health scores, sexual functioning, elimination problems, and weight loss. Other improvements included physical and social functioning measures of QOL, sleep disturbance, pain, and fatigue, as measured by The European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30). The EORTC-QLQ-C30 questionnaire has been demonstrated to be a reliable and valid measure of QOL (Aaronson et al., 1993). These findings of Knowles et al. (2007) demonstrate that nurse management of symptoms relating to bowel cancer might be beneficial. Nurses appear to play a key role in improving patient care, yet the limited literature available has demonstrated that further research exploring this position is necessary.

6.2.3 Exploring nurses' roles in physical activity counselling

The nurses' roles in physical activity counselling is not well defined as outlined previously in Chapter Two. Here, the two key qualitative research studies exploring the role of nurses in physical activity counselling will be discussed. In a case study of an acute surgical ward, the health promotion practices of the nurses working on the ward were observed (Casey, 2007a). Following the eight-week observation period, each observed nurse completed semi-structured interviews and the results indicated that they provided information and explanations as part of their health promotion practices. It was observed that nurses tended to give instructions to their patients, as opposed to working with the patient, to promote health and well-being. The lack of perceived shared care created a culture of task-oriented instruction on the ward which did not foster an environment where patients could feel empowered to participate in conversations about their care.

Nurses also appeared to rely on the perceived willingness of their patients to participate in physical activity or adhere to recommended advice to influence their practice. One study employed semi-structured interviews to explore the perceptions of healthcare professionals, including practice nurses, whose role was to promote physical activity through a national exercise referral scheme (Din et al., 2015). The interviews revealed that the national scheme was a useful referral option. However, many barriers existed to its implementation, such as healthcare professionals promoting physical

activity based on personal beliefs and judgements about the patients' motivation to change their current level of physical activity. The results of this research discovered a particular degree of health promotion bias which the authors suggested warranted further examination.

Based upon the aforementioned body of literature, it is, therefore, logical to explore the perspectives of nurses with particular regard to physical activity counselling and in conjunction with bowel disease. Nurses are highly involved in patient care, and their insight can provide valuable information on the efficiencies and inefficiencies of promoting exercise to patients, as demonstrated by Robertson, Richards, Egan, and Szymlek-Gay (2013). This suggests that nurses are in an ideal position to provide advice and counselling on health behaviours such as physical activity to bowel disease patients.

6.3 Method

6.3.1 Design

Semi-structured interviews have been selected as the desired medium because the flexibility of the structure of the interview script allowed for flexibility in learning about personal physical activity counselling practices. Previous knowledge of the clinical practices of physical activity counselling and discussions specific to bowel disease is scarce; therefore, the flexibility of semi-structured interviews assisted in gathering information on the diverse ways nurses may discuss exercise with bowel disease patients. Semi-structured interviews allowed the nurse participants to share their personal style and way of discussing exercise with their bowel disease patients.

6.3.2 Participants

All nurses who participated in this study worked on surgical wards and were involved in the care and recovery of people treated surgically for bowel disease. Fifteen nurse participants were recruited from private and public hospitals in the Brisbane and Gold Coast Area. Four interviews were conducted via telephone while nine interviews were conducted in person. Due to time constraints and staffing on the surgical ward during the scheduled interview day, two face-to-face interviews were group interviews

(two nurses completed one interview), and seven interviews were one on one individual interviews. Face-to-face interviews were conducted on the ward in a private room to ensure confidentiality.

6.3.2.1 Participant recruitment

Participants were recruited through the Directorate of Nursing at two hospitals. With permission from the Directors of Nursing, the researcher made several visits to the surgical wards of the individual hospitals to promote the study. Information statements were distributed to the staff (Appendix G). Nurses who worked with people with bowel disease following surgical treatment were eligible to participate. Eligible participants were then interviewed that day in person or scheduled for a telephone interview at a convenient time.

6.3.3 Interview development

The interview schedule was guided by phenomenology and developed with reference to the overall objective of this thesis, which was to understand how and in what context exercise is discussed among people with bowel disease. Reference to the findings of Chapter Four and Five and the available literature also informed the interview schedule for the current study. For example, based on previous research it was reported that healthcare professionals were more likely to discuss exercise with people who have other comorbidities (Kenzik et al., 2016). Therefore, questions seeking reflection on certain characteristics of patients with whom nurses typically discussed exercise was an attempt to broaden knowledge around this phenomenon. Similarly, supplying materials, such as brochures or videos, was reported to be successful at promoting physical activity (van Achterberg et al., 2011). The interview contained questions relating to the nurses' perceptions of bowel disease patients' reaction to the discussion(s), allotted resources and materials utilised to help discuss exercise with them, and how nurses encouraged them to exercise. Specific emphasis was placed on the general physical activity counselling discussions that nurses have with bowel disease patients and the information regarding exercise or physical activity that was shared.

The main focus of the interview was to understand how and in what context exercise was discussed with bowel disease patients. Based on the findings from Chapters

Four and Five that reported that the meaning of exercise varied based on the individual with bowel disease, it was important to explore the view of the nurses on what constituted physical activity and exercise. Therefore, nurses were asked to define what exercise and physical activity meant to them and how they defined these terms for their patients with bowel disease.

With the purpose of this research study in mind, the development of the interview schedule needed to explore the nurses' individual practices and nuances of counselling their bowel disease patients about physical activity. This included questions relating to discussion initiation and the context in which counselling might occur. Questions such as *"Can you describe an exercise discussion you'll have with your bowel disease patients?"* encouraged a detailed step-by-step explanation that made the process and the context of exercise discussions between nurse and patient even more clear. Questions such as *"How would you say these discussions are generally perceived by your patient?"* and *"How does your perception influence your discussion with current and future bowel disease patients?"* allowed the participant to reflect on their practice and share their thought process and any perceived bias when discussing exercise with their patients. The full interview schedule is presented in Appendix H.

6.3.3.1 Pilot interviews

Pilot interviews were conducted with four nurses. Similar to the pilot interviews conducted in Chapter Five, these interviews granted the opportunity for nurse participants to comment on the clarity of the interview questions. The pilot interviews were an important step in the refinement of the interview schedule because it helped to build a profile of normal nursing processes that could be incorporated into the interview schedule. One issue raised during the piloting process regarded the clarity of one of the questions asking nurses to define exercise and physical activity. The nurses suggested that this question should be simplified into two separate questions to settle any confusion about which term should be defined first. As a result, the interview schedule was modified.

6.3.4 Procedure

As mentioned in section 6.3.2.1 (*Participant recruitment*), permission was sought from the Directors of Nursing and Midwifery of one public and one private hospital to visit and recruit nurses on the surgical ward who cared for people with bowel disease.

Visits were made to the public hospitals to discuss the research with potential participants and exchange contact information to arrange a separate interview time. At the private hospital, the interviewer remained in a private room and waited until nurses that were interested in participating were available for face-to-face interviews or preferred to arrange an interview at a different time. Prior to each interview, participants were asked to read the information statement and sign a consent form (Appendix I).

The interviews took place at a time and location convenient for each participant. Face-to-face interviews with nurses from the private sector were held in a staff room that was made private for the duration of each interview or via telephone. Interviews with nurses from the public hospital were conducted via telephone or in a private office located at the hospital. It was important that the interview was conducted at a time and location least intrusive to the nurse and the ward.

6.3.4.1 Ethical considerations

Bond University Human Research Ethics Committee RO-1651, The Townsville Hospital and Health Human Research Ethics Committee HREC/15/QTHS/107, Mater Research Governance RG-16-035 and Gold Coast Health Research SSA/15/QGC/188 approved this investigation.

6.3.4.2 Data collection and analysis

A handheld digital audio recorder recorded the face-to-face interviews. Telephone interviews were recorded using TapeACall (TelTech. New Jersey, USA). An audio recording of the interviews is recommended because it allows for an organic flow of conversation and transcription by recall from notes is subject to interviewer recall bias (S. E. Kelly, 2012). Data were transcribed using professional transcriptionists (Rev.com. San Francisco, USA). Each interview was listened to and read through several times to ensure transcription accuracy and begin the analytic process. All interviews lasted between 20 to 30 minutes.

Following the recommendations of Braun and Clarke (2006), an ITA of the data set was performed based on the exploratory nature of this research (Vaismoradi, Turunen, & Bondas, 2013). ITA is flexible in its ability to be applied across multiple theoretical foundations and qualitative methods and still supply a detailed recount of the data set. Flexibility was necessary for this research because it allowed for an analysis of the practice of how nurses discussed exercise with people with bowel disease and added further understanding in regards to what physical activities the nurses considered to be exercise.

For this study, ITA was conducted manually. Highlighting phrases and statements within the transcript referring to exercise and the context in which the discussions occur achieved the first step of the analysis. As ITA was thoroughly discussed in Chapter Three, this section will provide an example of how the final themes were developed into initial codes specific to this data set (Table 6.1). Further examples of this data analysis are illustrated in Appendix J.

Table 6.1

Example of the development of a final theme

Initial note	Initial code	Provisional theme	Final theme
<i>Got to push</i>			<i>Managing</i>
<i>Not going to get better</i>	<i>Trying to</i>	<i>Handling resistance</i>	<i>patient</i>
<i>Trying to get them</i>	<i>encourage patient</i>	<i>from patients</i>	<i>resistance to</i>
<i>Your benefit</i>	<i>responsibility</i>		<i>engaging in</i>
			<i>exercise</i>

Regular meetings with the principal supervisor occurred where potential provisional themes were discussed based on the codes. The final themes were then checked to ensure they captured the data set and the narrative of the analysis as recommended by Braun and Clarke (2006). Participant recruitment continued until data saturation was considered to occur. This occurred when no new final themes emerged from the data.

6.4 Results

Fifteen participants were interviewed. Participant characteristics are outlined in Table 6.2. All participants were registered nurses. ITA of the results yielded three main themes. *The degree of physical activity and counselling* demonstrated that the definition and level of physical activity counselling was unique to the nurse participants and relied on their personal beliefs. *Managing patient resistance to engaging in exercise* encompassed the nurses' experiences of encouraging physical activity to their patients and how this experience affected their counselling practices. Finally, *managing conversational expectations in relation to other healthcare professionals* defines the world in which nurses navigate their role as exercise promoters and how this may be influenced by other healthcare professionals.

Table 6.2

Participant characteristics

Gender	
Male	3
Female	12
Age Range	
20-29	2
30-39	12
40-49	1
Hospital	
Public	8
Private	7

6.4.1 Theme one: the degree of physical activity and counselling

This theme illustrated the varying levels with which exercise and physical activity counselling transpired during consultations. Both the definition of what exercise is and the level with which it was discussed varied across the nurses and was unique to their personal counselling practice. This theme encompassed two subthemes; *exercise as a medical perspective* and *the calibration of physical activity counselling*.

6.4.1.1 Exercise as a medical perspective

This theme comprised the different definitions that nurses deployed to describe exercise to their bowel disease patients. There did not appear to be a uniform definition of exercise that the nurses described to their patients. Instead, exercise was defined based on personal perception. Nurses seemed to apply the term liberally to any physical movement. This included describing daily tasks such as showering and going to the toilet as exercise. One nurse commented when asked how exercise was defined:

*Watching them mobilise around the ward, mobilise around their rooms,
showering themselves, dressing themselves, simple things.*

Nurse 13. Lines 14-15.

This nurse defined exercise as tasks associated with daily living, such as getting themselves dressed and doing things for themselves. Exercise was defined by what others might view as usual recovery or returning to independence and not an idea separate from everyday activities. Another nurse commented:

*Exercise is just anything they do to prevent any adverse reaction or event so that
we can just get them going.*

Nurse 14. Lines 11-12

This defines exercise in regards to its purpose and it was applied to anything that helped bowel disease patients move on from the hospital without any complications from

surgery and provided the context for which exercise was discussed. However, it appeared that the definition of exercise was a means to an end. Additionally, exercise did not appear to be a separate topic or issue discussed in regards to the benefits of engaging in exercise activities.

Other nurses defined exercise relative to their own, as well as their patients', current physical capabilities. For example, one nurse said:

Whether it would be marching, walking, whatever they are capable of. Exercise to me would be like going for a bike ride, but they may not be at that level. Even if they're just lying in bed doing leg raises that's exercise to them.

Nurse 7. Lines 20-23.

This extract defined exercise based on the capabilities of the patient. Nurses appeared to understand that patients recovering from bowel surgery may not be capable of participating in certain activities such as bicycle riding. Nurse 7 defined exercise according to the context of the situation and capabilities of the patient.

The following extract illustrates a further perspective on the definition of exercise:

I don't really know, it's a hard one because, I think when you do think about exercise, as not being a patient, you think of going to the gym and doing hard-core exercise, whereas for a post-surgical patient, it's very different, it's perceived different. It's the little things like getting up and going to the toilet, showering yourself, all that kind of stuff, that is exercise for them, because it's hard work.

Nurse 5. Lines 204-208.

The nurses here have reflected upon the capabilities of a non-disabled individual and have adjusted the definition to suit the patients' current abilities. This suggests that nurses adapt the definition of exercise for the patients recovering from bowel surgery

based on individual capabilities. The data extract from Nurse 5 appeared to take an individualised approach to thinking about exercise for their bowel disease patients and defined exercise based on their perspective of what the patient was currently capable of performing. However, defining exercise based on perception has the potential to be confusing for patients who understand the definition of exercise as related to the abilities of health individuals who are unencumbered by illness or disease. This may discourage patients from exercising when asked to because they may believe they are incapable of performing such activities.

6.4.1.2 Calibration of exercise discussion in consultation

This subtheme revealed that nurses acknowledged deficiencies in the clinical conversations about exercise that they had with bowel disease patients. The nurses reported they did not provide their patients with enough information about exercise or discuss exercise as much as they thought they should. For example, one nurse said:

We probably don't say it to them as much as we probably should. We say the general benefits of it helping with surgery, but we don't usually say the general benefits of how it will help them in general. It would be the odd patient that you would say it to if you felt like you needed to. Probably, we don't say it as much as we should.

Nurse 3. Lines 180-184.

This extract recognised a lack of effort in discussing exercise with patients and that exercise was not considered as often or as frequently as would be expected in regards to educating bowel disease patients on the general benefits of exercise. It also appeared this nurse utilised personal judgements to help determine which patients would receive information about the general benefits of exercise. Another nurse explained:

I'm passionate about exercise, I love it. I think it's good for you. It probably is something we should talk about more, but I guess, it's difficult with knowing whether you're overstepping, giving people advice once they go home.

Nurse 11. Lines 133-135.

Nurse 3 and 11 also identified a lack of exercise information sharing with regards to the benefits of exercise for general health even though this nurse had recognised it as something that should be discussed by the nurse. However, there appeared to be boundaries with which nurses were conscious of in regards to offering exercise recommendations to patients once they leave the hospital. The data extract of Nurse 11 demonstrates how a lack of clarity in who is responsible for exercise promotion or whether bowel disease patients are interested in receiving physical activity counselling, effects the level with which the nurses discussed exercise with their patients with bowel disease. It was possible that a lack of education in regards to implementing such discussions or poor managerial support may have contributed to this. A lack of training was a recurring theme across the data set. These statements identify a part of clinical discussions about exercise that appeared to be overlooked, which was exercise for general health and well-being.

This theme also identified deficits in physical activity counselling based on the type of surgery from which the patient was recovering. For example, one nurse explained:

I guess those big procedures, we definitely always have the conversations, but I think sometimes the littler, like lap hemmies, [laparoscopic haemorrhoid surgery] or things like that might just get missed.

Nurse 5. Lines 273-275.

This nurse also recognised possible gaps in patient care and that the seriousness of the surgery dictated the degree to which exercise may be discussed. Additionally, there appeared to be a hierarchy regarding the seriousness of the surgery, which determined the extent of the nurses and patients exercise discussion.

6.4.2 Theme two: managing patient resistance to engaging in exercise

This theme described the nurse-patient relationship in regards to discussing and promoting exercise, addressed the conflict that nurses faced when encouraging exercise to their patients, and how they learned to manage patient resistance effectively. One extract explained:

Well, I don't really like, I'd never get cross with a patient. I don't really like trying to get them to do things when they feel they cannot. At the same time, you know it's benefiting them so they have to just do it.

Nurse 3. Lines 95-97.

This nurse expressed a struggle with managing patient resistance by encouraging exercise because of the benefits, yet not wanting to upset a patient. There seemed to be a struggle between doing what was best for the patient, such as encouraging exercise, yet caring for and understanding the patients' views and respecting their wishes, even if that meant allowing patients recovering from bowel surgery to be more sedentary and accepting the risks associated with it.

One way nurses appeared to manage patient resistance was through the help of fellow nurses. They seemed to rely on each other and worked together, which helped share the stress of encouraging uninterested patients to exercise. For example:

If worried that a patient hasn't gotten up all day, we'll hand him over so, like, just make sure you guys encourage mobility, but then sometimes patients need a bit of tough love. I mean yes, we want them to relax in here but at the same time, it's only going to create more complications if they stay in bed the whole day. The nurses are really good with picking up when they can see a patient's trying to slide under the radar and get away with not doing anything.

Nurse 1. Lines 54-59.

Similarly, nurses appeared to utilise patients' goals of returning home as a way of managing patient resistance to physical activity counselling. The nurses seemed to understand that many times the bowel disease patient wanted to go home and adjusted their initiation of exercise discussions around that goal. One nurse described it as follows:

Especially if they really want to go home, but they don't want to do anything about getting home as well. It's like well, if you're really keen to get home, then we are going to have to start to get you out, we are going to have to see you do this and this and this. Then, they start to realise, oh okay, I better do some stuff.

Nurse 3. Lines 118-121.

This suggests that nurses related to the bowel disease patients' desires and then adapted their practice accordingly, and appeared to be successful in regards to getting some of the patients active.

One way nurses encouraged mobility to their patients was through negative language, which appeared across the interviews. This meant that the nurses explained to the patients the consequences of being sedentary, for example:

There are those that are definitely more reluctant than others who just say, 'Let me lie in bed, let me be.' Sometimes you do have to take that harsh line with them and say, 'Well, if you do get hospital-acquired pneumonia, this is what could happen down the track, you could end up in ICU.' All that kind of stuff, so sometimes you've got to give them the worst-case scenario to promote the best options.

Nurse 5. Lines 59-64.

In this instance, the nurse placed the responsibility for health on the bowel disease patient. The nurse gave the patient the necessary information that allowed them to make an informed choice about recovery and the role of exercise in that recovery. Explaining the

immediate consequences of being sedentary appeared to be a major motivational means of getting patients out of bed and moving around. Another nurse said:

We inform them of the risk of what's going to happen if they don't mobilise and how it increases exponentially each day and each hour I mean when you tell someone, you know if you refuse to move for two days you will develop an ileus, your bowel will go to sleep, you will start to vomit your own faeces, I'll put a tube down your nose. They don't think it's really gonna happen to them but it's actually so common in post major bowel surgeries.

Nurse 15. Lines 205-210.

Nurse 15 has illustrated the process of explaining the consequences of being sedentary to patients recovering from bowel surgery. It seems this approach was deployed to perhaps scare their patients into becoming active by providing them with how their choice to be sedentary can result in further complications.

Patient positioning helped nurses to manage aspects of patient resistance, which meant acknowledging the patients' views regarding exercise. For example, when a nurse understood the beliefs that bowel disease patients had about exercise, only then could they effectively and efficiently tailor their exercise counselling to the specific patient. The views the nurses believed their patients held regarding exercise influenced the way in which they managed patient resistance. Sometimes this occurred because of nursing experience rather than a direct conversation with the patient. For example, when asked if certain characteristics determined whom exercise was discussed with, one respondent stated:

It depends on what the patient is like. I don't think you can have the same for every patient. I think it's very much, you walk in there and you sense what they are like and then you take your nursing into consideration and how can I get this person to work with me. Sometimes you have to be slightly offensive in a nice way.

Nurse 6. Lines 70-73.

Here, previous experience with patients recovering from bowel surgery helped the nurse to determine how the patient might respond to discussing exercise. Then, the nurse implemented a strategy that they believed would be effective in helping the patient. Additionally, this extract implies that the nurse becomes someone he/she did not recognise as he/she made “offensive” judgements of the patient in order to assist with encouraging physical activity. This extract justified being offensive for the benefit of the patient. When asked if exercise was discussed with all the patients one nurse said:

Um, not all of them. Just the ones we feel would benefit from it the most. The ones that lay in bed all the time and refuse to get up or don't want to get up and move.

Nurse 10. Lines 111-113.

This suggested that some nurses decided which bowel disease patients to discuss exercise with based on personal judgement and visual observations. It is the nurse who decided which patients recovering from bowel surgery would benefit from physical activity counselling. However, as the nurse indicated it is ‘we’ who decides it, it is suggested that it is a collective group effort in deciding which patients would benefit from physical activity counselling. There appeared to be an implicit bias in deciding which patients would profit from physical activity counselling. However, by including others in decision-making, personal implicit biases may not have been a leading factor when discussing exercise with patients recovering from bowel surgery.

The nurses also appeared to make judgements about bowel disease patients to explain the recovery process to them. One nurse explained:

Especially the older generation, because back 30 years ago when you had your appendix out you could spend a week and a half in the hospital and you would rest the whole time and you would lay flat and then when you stood up you would walk like this, but we're like no; no, you're up a couple hours past post-op to pass urine and then you're walking around and you walk as straight as you can and you walk and then you go home the next day. None of this sleeping for 24 hours.

Nurse 7. Lines 225-231.

This extract demonstrated some of the resistance received from a specific group of patients. In this instance, older people recovering from bowel surgery were positioned as accepting an established sick-role norm, which was that complete bedrest was required following surgery. The positioning of this specific population meant that the nurses could tailor the exercise discussions around this perception of many of their older patients. In this instance, positioning became an efficient way of establishing how to discuss physical activity with patients. However, another extract demonstrated:

I'm not necessarily going to have a very in-depth or even a conversation with a younger person. I think they're usually pretty enthusiastic to pick up and do things themselves. The physios tell them what they need to do and they usually just go from there.

Nurse 8. Lines 122-125.

This nurse positioned younger bowel disease patients as pro-active in their level of involvement in recovery. The extract also identified a particular level of trust within the younger population to be responsible for caring for themselves and a reduced dependence on nursing staff.

Advocating a new direction assisted nurses in managing the resistance of patients recovering from bowel surgery. This describes the context with which exercise was promoted to patients. Nurses described discussing exercise and promoting exercise as a way to help them resume normal activities following bowel surgery. This encompassed the promotion of exercise to help patients move forward toward a past self that was unencumbered by bowel disease and its associated treatment side-effects. It appeared the nurses discussed surgery for bowel disease as something that would not interfere with patients' future physical abilities or level of functioning. For example, one participant said:

So we really emphasise to try and go back to their actual life that they were doing before, so if they did do the walking, the swimming, the whatever they did, to try and go back to that and do what they were actually doing and if they were, to start off gentle, go for walks.

Nurse 12. Lines 21-25.

This extract described utilising the patient's pre-surgery activity levels and capabilities as a goal to strive for following surgery. The activities of the patient were exploited to help direct the exercise discussions and motivate physical activity. If the patient had been active before surgery, the nurse utilised this information to talk about exercise as a way to return the patient to their previous self. From this perspective, it appeared that exercise was also discussed in the context of restoring the patients' level of functioning seen prior to surgery. Another nurse said:

You're basically looking at the condition that they were beforehand and then trying to get them back to whatever they were before.

Nurse 4. Lines 154-155

Although exercise has many physical, emotional, and spiritual benefits, it seemed that most nurses discussed exercise with their patients as a means of them returning to the

norm or “actual life”. As demonstrated by the extract from Nurse 4, there appeared to be no mention about how a patient’s life would be different to how it was prior to surgery. Bowel surgery seemed to be a minor obstacle without possible life changing consequences for the patients.

6.4.3 Theme three: managing conversational expectations in relation to other healthcare professionals

This theme addressed the phenomenon of discussing and promoting exercise in relation to other healthcare professionals, namely surgeons, doctors, and physiotherapists at the hospital. The nurses described themselves as part of a multidisciplinary team that discussed exercise with the patients. The following extract demonstrates how they shared their practice:

I think nurses and physio on this ward work very well together in the sense that they’ll try to help you and you’ll try to help them. If they’re going to go into a patient before you’ve been in, they will get them up and put them on a shower chair. They really help us in that way. Then vice versa, if I go in or the physio needs help, we’re like, yeah... They are very good with us, because they know they need our help and we need their help. We work as a team.

Nurse 6. Lines 100-107.

This statement illustrates the relationship the nurse had with the physiotherapist in regards to mobilising the patient. The nurse appeared to incorporate aspects of their practice into the practice of the physiotherapist and vice versa. Each member seemed to help the other equally by assisting with the practice routines of each other. For example, another participant maintained:

Sometimes you have to be a little bit more forceful. You've got to go in and basically repeat yourself several times. Usually these people... The physios are also giving them education and that. We also get the doctors too, to come and tell them they have to get up and move more. It becomes more of team effort.

Nurse 4. Lines 96-99.

Here the nurse describes an instance in which they, the physiotherapist and the doctor, discussed exercise and its importance for patients recovering from bowel surgery. However, this statement also suggests that discussing exercise with patients became a group effort only after the nurse was unsuccessful in encouraging the patient to mobilise. This might be done for two reasons. The first could be that including more disciplines in exercise counselling would suggest exercise is indeed important. One nurse stated:

We'll say, they're a couple of days down the track we usually talk to the physios [physiotherapists] and the physios [physiotherapists] will say to us they'll recommend can you please mobilise this patient. We just want to probably pop two or three more walks in today. I'll go to the patient, I'll explain, I'll say, oh the physios [physiotherapists] have asked us to make sure we pop you up a few more times today, so if you want, do you want to pop up and we'll go for a walk. We usually just instruct them.

Nurse 8. Lines 6-11.

This extract describes the nurse as working under the supervision of the physiotherapists, as the physiotherapists recommended and instructed what the nurses should do regarding the promotion of physical activity and exercise to their patients. This suggested that a level of authority or a hierarchy existed within this shared role of discussing exercise with bowel disease patients. There appears to be a certain level of power held by the different members of the team within this role. It also appeared that the bowel disease patients recognise this division of power. One nurse described it thus:

We still do get those patients that anything a doctor says is the truth, you've got to do everything the doctor says, so I think when a doctor does say it, it probably carries a little bit more weight, which is sad, but it's definitely something that we could probably promote a lot more of.

Nurse 5. Lines 251-255.

This participant described instances in nursing practice where the patient believes that the role of the nurse did not include prescribing or promoting rehabilitation such as exercise. The nurse had to manage and navigate the level and depth of involvement of discussing exercise with these patients because it appears that the patients did not comply with nurse advice.

In addition, the nurses discussed working casually alongside physiotherapists and doctors or surgeons, yet also referred to complementing and supporting what the physiotherapists do or say. One nurse described it as follows:

We take sort of a minor role in it, we just try and encourage and reinforce what the physios [physiotherapists] put in place.

Nurse 14. Lines 32-33.

This participant is sharing their perceived role in discussing exercise with bowel disease patients as being in the background and discussing exercise as not something that is a part of nursing practice. For this nurse, initiating exercise discussions is not a shared role; it is the role of the physiotherapist, while the role of the nurse is to support the physiotherapist. Another explained:

When you've got everyone telling you, not just one physio [physiotherapists], because a lot of people don't like the physios [physiotherapists] just because they make them do things when they don't want to or when they're tired. I think it really helps that you've got people backing them up.

Nurse 9. Lines 152-155.

This extract encompasses the influence of physical activity counselling on patients when it occurred from several different sources. It demonstrates that a team effort or the shared role of counselling bowel disease patients recovering from surgery to be more active is an effective practice.

Some nurses also identified their role as filling in for the physiotherapist when one is not available. One nurse said:

Obviously, the physios [physiotherapists] aren't there all the time, so when the physios [physiotherapists] aren't there, the nurses take over that role.

Nurse 4. Lines 38-40.

This statement proposed that the nurses' role in regards to discussing exercise with patients is secondary to that of physiotherapists and only becomes a primary role in the absence of the physiotherapist. However, many of the nurses did not feel qualified or prepared to fulfil the role of the physiotherapist. The lack of preparedness influenced how nurses managed physical activity counselling with patients in relation to other healthcare professionals.

The level of readiness assisted nurses in managing the conversational expectations. This was illustrated in how the nurses approached discussing exercise with bowel disease patients. For example, these nurses discussed this during their group interview:

Nurse 6: *I think it's not something that is taught in nursing. It's not something that is taught. You learn it on the ward and you think....*

Nurse 7: *Maybe it should be something that is taught. We just identified that it's 1/3 of our practice. Maybe it should be something that is encouraged or at least identified as part of our role. I don't think it is. You learn it from other experienced nurses. You learn it from watching the physios and from surgeons and post-op plans.*

Lines 320-325.

These respondents described how approaching discussing exercise with patients was a learned skill gained through on the job training. This would suggest that nurses were unprepared in regards to discussing exercise with bowel disease patients. This also suggests nurses may not be sharing evidence-based information about the importance or benefits of exercise in managing symptoms of bowel disease due to the scarcity of education nurses receive about the benefits of exercise and how to best counsel their patients to become physically active. One nurse said, when asked if the shared role of discussing exercise with patients is best practice:

I think it would be good, but I think we need nurses to be more educated in terms of exercise because from an education point of view we aren't really trained in how to discuss with patient exercise or how to mobilise patients other than just the regular post-op mobilisation, so I think education is one we need because our physios aren't there all the time, so particular on weekends when patients go home on weekends we don't have that physio there. Yea, it falls back on us and often it's sub-par, I think.

Nurse 10. Lines 76-82.

This nurse expressed a common sentiment among those interviewed which was that the level of education they received in regards to how to discuss exercise with patients was lacking. The nurses appeared to rely heavily on reiterating and learning from the physiotherapists and the doctors. They also seemed to want to discuss and provide information about exercise to patients because they appeared to understand the benefits of being active, yet felt the quality of- and the way to approach the topic, was inadequate.

There also appears to be internal dialogue occurring within the nurse about what is actually expected in terms of discussing and promoting exercise to bowel disease patients. For example, this extract explained:

I guess it's just trial and error so learning how to relay the information each time I guess will be different. I guess once you see how a patient responds to what you said specifically, obviously next time well, oh, that worked really well and that was a huge motivator so obviously I wanna work that into my discussion now.

Nurse 13. Lines 69-73.

This nurse disclosed feeling uncertain about what sort of exercise information to give to patients. Feelings of wanting to promote exercise and physical activity are simultaneously presented alongside a sense of doubt in how to discuss exercise with patients and promote it safely. This suggests that the education nurses receive in regards to exercise promotion or prescription may not be preparing them to discuss exercise with patients confidently. This creates a clinical discussion about exercise that may potentially leave the patient feeling uneasy or unsure about what is expected of them. Furthermore, the patient may feel less confident in the level of care received by the nurse.

6.5 Discussion

This analysis identified three themes that defined nurses' experience discussing exercise with people with bowel disease recovering from bowel surgery. The first theme, *the degree of physical activity and counselling*, demonstrated that the definition and level of physical activity counselling provided by nurses to their bowel disease patients exhibited considerable variation between the nurses. The second theme, *managing patient resistance to engaging in exercise*, encompassed the nature of the nurse-patient relationship in regards to physical activity counselling and finally theme three, *managing conversational expectations in relation to other healthcare professionals*, describes the experience of the nurse as part of a multidisciplinary team.

Firstly, the term "exercise" or "physical activity" does not have a universal definition within physical activity counselling. This was conveyed through the first theme: *the degree of physical activity and counselling*. This theme described the different ways the nurses defined exercise in relation to the counselling of their patients with bowel disease and recovering from bowel surgery. It can be speculated that the

definition of exercise outlined in the literature was not suitable to what the nurses deemed appropriate for their patients. However, a definition of exercise relative to these patients' needs should be made. This is because a varied definition of exercise might have negative consequences in regards to patient care and what is expected of the patients from nursing or other healthcare professionals. For example, one study of the experiences of nurses who identified health promotion as part of their role, struggled to define the term (Casey, 2007b) and identified barriers such as health promotion not being appropriate for all patients over the age of 65 (Kelley & Abraham, 2007). As such, a need to clarify health promotion has been recognised (Goodman, Davies, Dinan, See Tai, & Iliffe, 2011). Similar conclusions may be drawn for the need to define exercise and physical activity for nurses who care for bowel disease patients. Such definitions might provide nurses with more confidence in discussing exercise with people with bowel disease under their care.

The nurses in this study described the ways in which they provided physical activity counselling to their patients. For many of them, the level of information they shared was sub-par and was described by the subtheme: *Calibration of exercise discussion in consultation*. This subtheme detailed the nurses' feelings that they were not discussing exercise with their patients as extensively as they should. One reason for this may include lack of training in exercise counselling or knowledge of the benefits of exercise. However, the only available study of oncology nurses demonstrated that nurses were aware of the many benefits of exercise for people with various cancers (Karvinen et al., 2012). Unfortunately, the findings were the result of a survey of nurses that cared for a variety of cancer types, so it is unknown if nurses are aware of the benefits of exercise specific to bowel cancers. Furthermore, information regarding the physical activity counselling practices of nurses for people with IBD have not been previously investigated. The nurses in the current study mentioned a need for more education about physical activity counselling, suggesting they may be unaware of the specific benefits of exercise specific to bowel disease. Similar studies in primary care have identified a lack of education contributed to the absence of physical activity discussions between nurses and patients (Abramson, Stein, Schaufele, Frates, & Rogan, 2000; Lobelo, Duperly, & Frank,

2009). Therefore, it can be suggested that nursing staff across the healthcare system may benefit from training and education in physical activity counselling.

It was revealed that one context with which nurses encourage exercise among their patients recovering from bowel surgery was through outlining the negative consequences associated with physical inactivity. Adapting a physically active lifestyle was reported to be reliant on gain-framed messages, with gain-framed messages defined as highlighting the benefits of participating in a particular behaviour (Gallagher & Updegraff, 2012; van 't Riet, Ruiter, Werrij, & de Vries, 2010). A systematic review of message-framing literature reported that the greatest changes in behaviour occurred when the message was framed based on the individual for which the message is directed (Covey, 2014). This review reported the success of gain-framed or loss-framed messages is heavily reliant on the beliefs, self-efficacy, and goals of the message receiver. For example, people who reported high self-efficacy to quit smoking responded better to loss-framed messages, meaning they reported feeling more motivated to quit smoking, than when they received gain-framed messages (Riet, Ruiter, Werrij, & de Vries, 2008). In this current analysis, it is possible that using loss-framed messages to encourage people to participate in exercise was only successful for certain patients. Future research should explore the application of gain- and loss-framed messages to promote exercise to bowel disease patients to determine the effectiveness of these approaches in improving patients' willingness to participate in exercise. Furthermore, the nurses did not mention discussing with bowel disease patients' exercise or lifestyle activities following hospital discharge.

Patient positioning demonstrated how implicit biases held by some nurses may have influenced the physical activity counselling they provided some of their patients with bowel disease. The data appeared to demonstrate that physical characteristics, specifically age, helped determine the patients with whom to discuss exercise. It seemed to some nurses that older bowel disease patients were in need of more encouragement because of assumptions regarding the necessity of bedrest post-surgery. This was due to the patients' perceived lack of awareness about the benefits of exercise for bowel disease symptoms. These expectations may potentially set a dangerous precedent where some patients might be overlooked or not receive the level of information they desire or require based on their age. The results of this study are commensurate with other research that

reported nurses believed that older patients required the nurse to take control of care (Casey, 2007b; Kelley & Abraham, 2007) or prescribed exercise based on other physical characteristics such as physical appearances or condition (Din et al., 2015).

Managing conversational expectations in relation to other healthcare professionals described how the nurses' roles in discussing exercise varied and were dependent on the perceived roles of, and support provided by, the other healthcare professionals within the hospital. The balancing of these expectations meant that the nurses controlled their degree of involvement in physical activity counselling as well as the level of detail given to patients recovering from bowel surgery about exercise. The role of the nurse in discussing exercise with patients appeared to be in a constant state of change and dependent on how the other healthcare professionals navigated their own role in discussing exercise. This finding appears consistent with emergency care nurses who reported conflicting roles in health promotion (Duignan & Duignan, 2017; Shoqirat, 2013). Some emergency care nurses identified health promotion as not being a part of their role, indicating other nurses and healthcare professionals at the hospital should promote health. Even the other emergency healthcare nurses who reported offering some health advice to their patients, explained that they did not play a major part in health promotion. Similarly, nurses in this current study found themselves navigating their purpose in discussing exercise with patients with their perceptions of the responsibilities of the other healthcare professionals in the hospital. This is supported in the literature as the role of nurses in the promotion of healthy behaviours, including physical activity, reported team-work as an effective skill required to promote healthy behaviours to patients (Irvine, 2005; Jerdén, Hillervik, Hansson, Flacking, & Weinehall, 2006; Kemppainen, Tossavainen, & Turunen, 2013). Therefore, when effective multidisciplinary practice is not occurring, it is quite possible that nurses and other healthcare professionals will limit their physical activity counselling as they believe it may be someone else's primary responsibility.

There are some limitations to this study. First, as not all interviews were one on one interviews, this may have affected the discourse that occurred during the interview. It is possible that by two nurses sharing their experiences simultaneously they may have felt hesitant towards sharing particularly personal information, thereby influencing the results

of this study. However, group interviews also create certain dynamics that cannot be achieved during a one on one interview, such as the ability for participants to trigger memories or stories as result of sharing experiences with each other. These dynamics may have added further detail about the experiences of discussing exercise with people recovering from bowel disease surgery. Further research should explore the influences of qualitative methods on the collection of data from surgical nurses. Secondly, semi-structured interviews were conducted with only one group of healthcare professionals i.e. nurses, based on the findings within the literature that identified nurses as the preferred source for health-related information for patients. Further, the experiences of only one sub-group of nurses i.e. surgical nurses was explored. The perspectives of other healthcare professionals and non-surgical nurses that care for people with bowel disease were beyond the scope of this thesis and therefore not explored. It is possible that by including other healthcare professionals, such as physiotherapists, surgeons, and nurses that work in out-patient care, that a greater understanding of how and in what context exercise is discussed with individuals with bowel disease could be made. However, as the literature surrounding the role of physical activity counselling for people with bowel disease is scarce, interviewing a variety of healthcare professionals that care for people with bowel disease may have yielded little information about the role of specific healthcare professionals in physical activity counselling. Identifying the healthcare professionals, such as which sub-group of nurses, physiotherapists, or surgeons, who may be most appropriate to discuss physical activity with bowel disease patients, is important to patient care. Incorporating multiple healthcare professional disciplines in the semi-structured interviews may have led to greater confusion in regards to how physical activity counselling should occur for people with bowel diseases. To address this limitation, future investigations should build on the findings of this research to investigate other healthcare professionals, such as physiotherapists, surgeons, and non-surgical nurses, and their role in physical activity counselling for people with bowel disease.

A third limitation of this study is that the interview schedule did not differentiate between physical activity counselling practices for people with bowel cancer versus the counselling practices for people with bowel disease. It is possible the nurses may have

approached their patients differently based on the specifics of their bowel disease diagnosis. However, the nurses in this study did not differentiate between their patients with bowel cancer or IBD recovering from bowel surgery, which may suggest that nurses approached exercise counselling for each patient group equally, regardless of the type of bowel disease. However, as the age of people diagnosed with bowel disease may vary, younger people are more likely to be diagnosed with IBD (Twedell, 2008), the implicit biases previously discussed, such as age, may have influenced which bowel disease patients were least likely to receive an exercise recommendation. This means that people with IBD may have received less information about exercise as a result of their younger age.

In conclusion, the analysis of the data revealed that the nurses' role in physical activity counselling for bowel disease patients is not clearly defined and this lack of clarity negatively influences the experience some nurses have when discussing exercise with their patients. The three themes identified within the data suggest that the nurses experience general uncertainty when discussing exercise with their patients recovering from bowel surgery. How the nurses defined exercise, the information about exercise they shared with patients with bowel disease, and how they managed the conversational expectations demonstrated this lack of clarity. Additionally, the context in which physical activity counselling occurred was in relation to recovery and rehabilitation and an opportunity to take advantage of encouraging exercise for general health benefits appeared to be missed.

6.5.1 Reflexivity

The nursing staff shared the desire to help people with bowel disease become active. However, they expressed that they were inadequately prepared to do so. The uncertainty of how to help was a feeling that resonated with me based on my previous experiences with my friend who died from bowel cancer. As I was a teenager at the time of her diagnosis and ultimately her death, I too felt ill-equipped to provide her with any help or guidance. Although it was not my responsibility to fill that role, and it was not expected of me, I felt helpless all the same.

These feelings of sympathising with the nurses in regards to wanting to provide physical activity counselling, yet not being trained to do so, became very present during the data analysis phase. While immersing myself in the data and conducting the line by line analysis, a common pattern emerged that encompassed the lack of information about exercise being shared by nurses. Although this was a clear theme, I struggled with due diligence of providing a provisional theme because I felt guilty about what that theme would imply about the nurses I had interviewed. As I had previously learned the importance of supervisor support and communication during the analytic phase of Chapter Five, I expressed my hesitation to my primary supervisor and through our discussions, it became clear that I was projecting personal beliefs into the process. To address this, I returned to the data and focused on the patterns in the data set. I followed the recommendations of Braun and Clarke (2006) and created provisional theme names that encompassed a description of what the data showed.

It was during these moments where I believe I grew the most personally and as a qualitative researcher. I learned about the importance of being able to put personal convictions aside as well as worrying about how something may appear to someone else based on those beliefs. I also learned to trust the qualitative process. The methods work if they are followed and a consciousness of personal beliefs and convictions is held throughout that process.

6.6 Conclusion

In conclusion, an ITA of the interviews with nurses revealed that the roles of nurses in physical activity counselling are complex because nurses appeared to navigate their responsibilities within the roles of the other healthcare professionals, namely physiotherapists, surgeons, or doctors. Also, the nurses seemed to manage the level of information about exercise they shared with their patients based on their perceptions of what the physiotherapists and/or surgeons had shared. The results of this study suggested that the nurses identified having a role in physical activity counselling; however, the details of this role were unclear and may be dependent on the practices of other healthcare professionals. The nurses' promotion of physical activity and exercise

appeared to focus on recovery from bowel surgery, with considerably less of these discussions focusing on the wider health and well-being benefits of being physically active. Further research should explore which healthcare professional is best suited to discuss the wider benefits of physical activity and exercise with patients with bowel disease recovering from bowel surgery.

The results of this study highlighted the need to clarify the roles of different healthcare professionals in discussing exercise with patients. The unclear understanding of which discipline is primarily responsible for exercise counselling may have the potential to impact the quality of patient care. There is the possibility that some patients with bowel disease may not be receiving the level of care they needed or expect and this may have negative consequences on their recovery. Future research should explore defining physical activity counselling roles for healthcare professionals and how best to provide this in a multidisciplinary environment.

The findings also highlighted that the definition of exercise applied by nurses when counselling people with bowel disease has yet to be determined. The definition of exercise understood by the nurses in this study was largely reliant on personal perceptions. This may translate into patients feeling unsure what is expected of them regarding their expectations to exercise following surgery. Additionally, this may potentially lead to nursing staff unknowingly sending unclear or mixed messages regarding the mode, intensity, and frequency of exercise that is expected of the patients.

The themes acknowledged within this study provided valuable information relating to the nurses' role in physical activity counselling. This exploratory research identified further investigation is needed to clarify the roles of healthcare professionals in discussing exercise with people with bowel disease recovering from bowel surgery. Hospital stakeholders may utilise this information in more clearly defining the roles of healthcare professionals within the hospital and how they can best work in a multidisciplinary fashion to improve patient outcomes. Furthermore, physiotherapists and surgeons can apply this information to assist in developing a definition of exercise for people with bowel disease.

In conjunction with Chapters Four and Five, this final study has added further knowledge into the role of exercise for people with bowel disease. Through the analysis of nurses' experiences discussing exercise with people with bowel disease, it became clear that while exercise and physical activity counselling for people with bowel disease is important to patient care, the exact healthcare profession responsible for implementing this practice is unknown. The next chapter will further discuss the findings from the three studies of this investigation in more detail and in relation to the discussion of the literature in Chapter Two. Chapter Seven will also discuss the limitations and implications of this research programme.

Chapter 7

Advancing the role of physical activity counselling in bowel disease care

7.1 Introduction

This thesis began by exploring how and in what context physical activity is discussed among people with bowel disease. There were other questions that emerged as being able to contribute to this primary aim, including:

- How do people with bowel disease discuss exercise among themselves?
- What perceived role does exercise have for people with bowel disease?
- What are the practices and discourses of physical activity counselling?
- What are the perceptions of physical activity counselling among nursing professionals and people with bowel disease?

As opposed to exploring physical activity counselling using quantitative methods, this thesis applied qualitative methods to collect data from online discussions and semi-structured interviews, with the intention to gain more insight into how people with bowel disease discuss exercise with each other and experience physical activity counselling. The semi-structured interviews also added insight into the experience of health communication from the perspectives of bowel disease patients and nurses who care for them following bowel surgery. The questions above led to interpreting how and within what context people with bowel disease discussed physical activity through three distinct studies that are presented in Chapters Four, Five and Six. Symbolic interactionism and phenomenology, in conjunction with the analysis of online discussions and semi-structured interviews, contributed to advancing the knowledge of health communication between people with bowel disease and bowel surgery care nurses. This chapter will examine how the findings of the three studies addressed the main research aims, how the findings compared to the literature, and the primary implications of these results to improve care for bowel disease patients. This chapter will also address the limitations of this thesis as a whole before concluding with the development and summary.

7.2 How and in what context is physical activity discussed among people with bowel disease?

It became clear from the data generated across the three separate qualitative studies that people with bowel disease and their nurses viewed physical activity as having different roles within patient care, and discussed exercise and physical activity within the context of these roles. Therefore, to answer this question, it is important to consider the role of exercise for people with bowel disease from the perspectives of those with the disease as well as their nurses.

7.2.1 What perceived role does exercise have for people with bowel disease?

Research has illustrated that physical activity and exercise hold positive roles in the lives of people with bowel disease. This has mainly been achieved through analysis of surveys and measuring scales to determine statistically significant benefits. For instance, physical activity was associated with significantly improved measures of quality of life (QOL) and decreased fatigue for people with bowel disease (Husson et al., 2015; Packer et al., 2010). However, relatively little is understood concerning the personal experiences of people with bowel disease regarding physical activity and the impact of these experiences in their day-to-day life (Rice & Ezzy, 1999). For example, Chapter Four revealed that people with bowel cancer participated in exercise as they perceived it to be capable of saving their lives and viewed it as an extension of their treatment. Findings from Chapter Five indicated that the experience of exercise provided people with bowel disease the mental clarity they desired to meet the cognitive demand of their daily lives. Analysis of semi-structured interviews in Chapter Six provided a perspective into how the role of exercise is managed by a specific group of healthcare professionals that cares for people with bowel disease, which provided insight into how the sharing of information about exercise between bowel disease patients and nurses may affect the perceived quality of care. This information, as gathered through qualitative methods, provides great detail into the function of exercise for people living with bowel disease.

Across the first two studies, it became evident that exercise has a role in the lives of people with bowel disease. The findings from Chapters Four and Five demonstrated that people affected by bowel disease participated in exercise activities because of the

many benefits they received. In examining these benefits, it was revealed in Chapter Four that people with bowel cancer enjoyed mental, physical, and spiritual benefits. This is substantiated by the findings from Chapter Five, which add further information about the benefits of exercise for people with other bowel diseases, namely IBD. As the benefits of exercise for people with bowel disease have been previously reported in the literature (Bilski et al., 2014; Perez, 2009; C. Taylor et al., 2010), this was an expected finding of this research programme. However, the benefits of exercise as mentioned previously, such as the improvements in body composition and physical fitness, may not necessarily be perceived as having a direct effect on the ability of people with bowel disease to complete activities of daily living, their overall QOL, or general well-being. Therefore, these current findings, obtained through qualitative measures, provide a greater understanding of the importance of exercise for people with bowel disease operating within their daily lives. Additionally, these findings substantiate the findings of Chae et al. (2016) in that people with bowel disease enjoyed exercise. However, as this is a small body of literature, the findings from the first two studies of this thesis may provide further evidence and lead to an increase in the appropriateness of exercise for people with bowel diseases.

These benefits, described in Chapters Four and Five, as mental, physical, and spiritual helped people confront the many challenges they faced as a consequence of bowel disease. It was revealed that exercise assisted participants regain control of their bodies, while others described the ability of exercise to improve mental health. As a result, it can be suggested that people with bowel disease perceived exercise to play a central role in their daily lives. The benefits of exercise, as perceived by nurses who care for people with bowel disease and described in Chapter Six, demonstrated that they promoted exercise to reduce the risks of post-operative complications. Encouraging exercise, specifically walking, has been demonstrated to reduce complications from bowel surgery and resulted in early hospital discharge (Bradshaw, Liu, & Thirlby, 1998; Q. Wang et al., 2012). Therefore, as the findings across the three studies revealed that exercise was considered beneficial for people with bowel disease, it can be suggested that exercise can play a key role in improving their lives, through improving QOL and mental health, or reducing the risk of complications following bowel surgeries. However, these

findings show that individuals with bowel disease and the nurses that care for people with bowel disease recovering from surgery viewed the role of exercise differently.

The differences in the perceived role of exercise between nurses and people with bowel disease appeared to affect the frequency, quality, and topics discussed within conversations about physical activity between nurses and people with bowel disease. For example, Chapters Four and Five demonstrated that people with bowel disease discussed exercise and physical activity as a valuable component of their long-term recovery, such as improving sleep, QOL, and general mental health, while Chapter Six articulated that nurses defined and discussed exercise in relation to recovery from surgery and promoted exercise to their patients as a means of early discharge and avoiding post-operative-surgical complications. Chapters Four and Five revealed that people with bowel disease did not receive sufficient physical activity counselling, while Chapter Six demonstrated that, although the quality was low, physical activity counselling was reported to generally occur. Therefore, the context within which physical activity counselling occurred was in relation to the participants' perceived role of exercise. The analysis of Chapters Four and Five indicated that people with bowel disease appeared to equate physical activity counselling with receiving information about long term care, while the findings from Chapter Six indicated that physical activity counselling provided by the nurses focused on recovery from surgery and did not encompass discussions about the benefits of exercise for long-term care.

People with bowel disease did not view exercise as offering benefits in physical appearances, but rather connected to exercise on a deeper and more spiritual level. The participants in Chapters Four and Five described the deep spiritual connection with exercise through their personal experiences. Via an online support group (Chapter Four), forum contributors shared these deep connections to motivate others to participate in exercise activities. In the online forum, members with bowel disease discussed the role that exercise played in allowing them to reconnect with life. Similar findings were demonstrated in semi-structured interviews with individuals with other bowel diseases, including IBD (Chapter Five). The participants shared many of these same feelings, attitudes, and connections with exercise. For them, exercise was a way to improve the illness experience as opposed to reducing disease risk. Reducing disease risk was

commonly referred to in Chapter Six. In this way, exercise was viewed as enriching benefits by people with bowel disease and reducing potential complications with surgery by the nurses that cared for them.

This investigation also found that the definition of physical activity was not consistent across those living with bowel disease or the nurses who care for people affected by bowel disease recovering from bowel surgery. The definitions ranged from any physical movement to physical activities requiring specific structure and planning. Specifically, Chapter Four showed that patients viewed some activities as not “real exercise.” Patients and nurses may experience difficulties in meeting each other’s needs without clarifying what actually constitutes exercise. It was noted in the literature that when nurses told people with bowel cancer to “build themselves up” to refer to increasing muscle mass, this was perceived by individuals with bowel cancer to mean gaining weight and unrelated to improving physical fitness and function (Anderson et al., 2010). These two separate interpretations of this advice may have negative consequences, as unhealthy weight gain can lead to further complications associated with bowel surgery (Wu, Zhu, Kiran, Remzi, & Shen, 2013) or declines in general overall health. To ensure people with bowel disease and nurses understand the advice or information shared, it is suggested that both the patients and nurse agree on what constitutes exercise prior to any engagement in physical activity counselling. For safe and effective physical activity counselling to occur, it would seem essential for the definition of terms to be clearly understood among all stakeholders. An unclear understanding of terms can affect the practices and discourses of such discussions. This will be discussed in the next section.

7.2.2 What are the practices and discourses of physical activity counselling?

Despite the exercise and physical activity guidelines that have been outlined to include people with bowel cancer or IBD (Ball, 1998; Schmitz et al., 2010), the advice and recommendations shared during physical activity counselling relied heavily on the context within which it occurred. Across the three distinct studies of this thesis, there was little mention of the current physical activity guidelines for people with bowel disease. More commonly mentioned were individual approaches and exercise routines that were based on the perceived personal capabilities. Chapters Four and Five

demonstrated that people with bowel disease sought advice from similar others or relied on personal instincts to determine the intensity, frequency, and duration of exercise that was suitable for their needs. Chapter Six illustrated similar findings in that the nurses often applied their personal perceptions of patients' capabilities or patients' interests in receiving exercise advice.

Chapters Five and Six explored the practices of physical activity counselling from the perspectives of those with bowel disease and the nurses involved with bowel disease care. Exploring the nurses' perspectives and, ultimately their experiences of such practice, achieved considerable insight into the practice of physical activity counselling. The findings demonstrated that this practice did not exist as part of usual care; therefore, the level with which physical activity was discussed depended greatly on the ease with which the nurse was prepared to discuss exercise or physical activity with their patients. Lack of education and training as barriers to physical activity counselling as reported in Chapter Six have been previously indicated by nurses in primary and cancer care (Eakin et al., 2005; Hebert et al., 2012; Karvinen et al., 2012; Stevinson & Fox, 2005), indicating that nurses may benefit from physical activity counselling training programs. Additionally, the patients' perceived willingness to adhere to physical activity advice further influenced the physical activity counselling practices of the nurses. For example, nurses managed their practice based on the perceived beliefs the patient had towards exercise. In many cases, nurses positioned patients based on physical characteristics, such as age or physical appearance, as needing or not needing physical activity counselling. The perceived willingness of patients to follow the nurses' advice to participate in exercise activities is in line with previous research (Karvinen et al., 2012).

However, Chapter Six also demonstrated that the physical activity counselling practices of nurses were influenced by the counselling practices of other healthcare professionals involved in the care of people with bowel disease. For example, many nurses described their practice of discussing exercise with their patients as providing "back-up" or supporting the counselling practices of other healthcare professionals such as physiotherapists or surgeons. Although many nurses believed that physical activity counselling was part of their responsibilities, they expressed their role as being part of a team approach towards physical activity counselling that involved all members of the

healthcare team. This is in contract to other research indicating that nurses perceived themselves to be the primary healthcare professional group responsible for promoting physical activity to their cancer patients (Keogh, Puhlinger, et al., 2017). Whitehead (2005) supports the findings of Keogh et. al (2017) and argues that the shared role may not be the most effective means of health promotion and provides an argument which suggests that nurses should take a lead role in promoting health behaviours to patients as they are the largest healthcare professional workforce located in hospitals. However, it was also argued that support from key stakeholders in hospitals is needed for this shift to occur.

The nurses described experiences where they provided patients with the worst-case scenarios as sources of motivation for patients. These experiences left many nurses conflicted in regards to doing what was best for the patient and following hospital protocols, yet wanting to abide by the wishes and values of the patients who were reluctant to become more physically active. This type of practice, that includes wanting to appease the wishes of the patient, recognises that not all policies will fit every patient's needs and an understanding that hospital policies and procedures will guide practice and not necessarily dictate it (Mannix, Wilkes, & Daly, 2015). This finding is important as it presents a perspective to consider in regards to the dissemination of physical activity guidelines into nursing practice. This provides considerable insight into the practices of physical activity counselling from both a personal and professional level and provides a foundation on which to build future investigations, clarifying the responsibilities of healthcare professionals in physical activity counselling for people with bowel disease.

7.2.3 What are the perceptions of physical activity counselling among nursing professionals and people with bowel disease?

The data generated from all three studies demonstrated that people with bowel disease and the nurses involved in bowel disease care were in general agreement in regards to the importance of physical activity counselling. As mentioned previously, the findings from Chapter Six indicated that nursing professionals perceived physical activity counselling to be part of their role, yet the level within which they engaged patients in physical activity counselling varied. The perceived uncertainty of the nursing role was

similar to another study where nurses reported that health promotion was part of their responsibility, but they were unclear on their exact roles (Casey, 2007b). Based on the experiences of people with bowel disease, the source or provider of the counselling was much less important than the counselling practice itself. However, nurses and patients may have different expectations regarding where responsibility to initiate such discussions lies, creating a possible imbalance in the nurse-patient relationship (Stoddart, 2012). For example, the nurse might feel the patient will initiate exercise discussions if the patient is interested in adopting an active lifestyle or is concerned about the ability to return to an active way of life. The patient may feel it is the nurse, or other healthcare professionals' role to initiate exercise discussions, as doing so might mean it is safe and/or beneficial for the participant to engage in such activity. Additionally, asking such questions about the potential benefits of exercise may be challenging for some patients (Casey, 2007a). Chapter Five demonstrated this, wherein some people with bowel disease revealed how not discussing exercise with any members of their care team led them to believe that exercise was not relevant to their care and recovery and therefore, did not raise the topic during their discussions.

It was the perspectives of the people with bowel disease in Chapters Four and Five that demonstrated the importance and priority they placed on physical activity counselling. In Chapter Five, the bowel disease participants' perceived lack of physical activity counselling from their healthcare professionals meant that many expressed the view that they did not receive the level of care they needed and deserved. Similar findings suggest that people with disease and under the care of nursing staff rely on the information shared by them to measure the quality of their care (Bertero et al., 1996; McCabe, 2004). In Chapter Six, the nursing perspective was able to provide some insight into why the practice of physical activity counselling may be lacking from patient care. Some reasons included a lack of training and uncertainty of their role in relation to the role of other healthcare professionals on the ward, namely physiotherapists and surgeons, in regards to physical activity counselling. These findings demonstrate the importance of future investigations aimed at exploring how to effectively provide nurses with the resources they require to meet the physical activity counselling needs of their patients

with bowel disease and how this might be conducted as part of a larger multidisciplinary approach.

An important finding of this research is the difference with which people with bowel disease and the nurses who care for people with bowel disease perceived the purpose of physical activity counselling. The analyses of data collected in Chapters Four and Five indicated that people affected by bowel disease perceived physical activity counselling to relate to learning about the benefits of exercise and how to participate in exercise for long-term health. This contrasted with the analysis of semi-structured interviews in Chapter Six that demonstrated that the nurses provided information to their patients about how exercise can assist them with recovery from surgery. The difference in emphasis of physical activity counselling from the individuals with bowel disease and the nurses' perspectives did not appear to meet the needs or expectations of those with bowel disease. This suggests that additional work needs to be done to better align the patient and nurses' perspectives on physical activity counselling if patient outcomes are to be optimised.

7.3 Implications of these findings

The discussion above provides a greater understanding of how and within what contexts physical activity counselling occurs between people with bowel disease and the nurses responsible for their care. These findings have implications for the future of physical activity counselling that are worthy of discussion.

The findings of this programme of research indicate that discussing exercise or physical activity has a beneficial role in bowel disease care. People with bowel disease illustrated the physical and psychosocial benefits that exercise provided to them. Both online via the online support group and during the semi-structured interviews, people affected by bowel disease discussed the wide variety of benefits of exercise. These findings imply that individuals with bowel disease would benefit from the development of physical activity or exercise guidelines designed specifically for them. Current guidelines established by the ACSM and NPAGA for people with bowel cancer and the exercise guidelines established for people with IBD (Ball, 1998; Schmitz et al., 2010) are

not specific enough to the unique needs of people with bowel disease (such as the need to refrain from being too far from the toilet during an exercise bout) or do not provide sufficient specific guidance in how to regain an active lifestyle. New guidelines should clearly define physical activity and exercise to eliminate any confusion about what constitutes exercise. Advice to return to “normal activities” requires clarity as expressed by the findings of Chapter Five. Exercise guidelines would also benefit from considering the different types of bowel surgeries, as physical restrictions and recovery times will vary as explained in Chapter Six.

It is evident from this research that the definition of exercise varied within and between the nurse and patient groups, some people with bowel disease expressed not being able to participate in the amount of exercise perceived to be required to obtain health benefits. Furthermore, the unclear definition of exercise became a source of conflict in the online forum described in Chapter Four. In that particular medium, people with bowel cancer who were unable to participate in or envision other members’ expectations of exercise, appeared to be berated for not taking survivorship seriously, which affected the level of readiness to participate in exercise among some members. Additionally, the findings from Chapter Five demonstrated similar confusion as to the definition of exercise, where people who were active did not identify their activities as being a form of exercise. Although the repercussions for varying definitions of exercise did not exist among the participants in Chapter Five, the lack of a clear definition may have implications when discussing exercise with care team members. As demonstrated by the results of Chapter Six, the definition of exercise and physical activity also varied in the nurses who provided care to individuals with bowel disease. To fully appreciate physical activity counselling, clear definitions should be established and agreement reached between the patient and nurse regarding what constitutes exercise. Definitive meanings may lead to an increase in the satisfaction of care. Chapter Five demonstrated that the lack of physical activity counselling contributed to detrimental effects to care team-patient relationships. Inadequate counselling also influenced the perceived importance of exercise for improving specific psychological and physical complaints.

Furthermore, these two opposing views on what comprises exercise or physical activity may have further implications in regards to the willingness of people with bowel

disease to participate in physical activity counselling and adhere to recommended advice. It may be that discussing physical activity and encouraging people to exercise while using negative connotations was not an effective communication strategy. This was especially noted in Chapter Four as some people with bowel disease (bowel cancer specifically) had lost faith in the ability of exercise to keep them healthy. Therefore, if nurses are counselling people with bowel disease on the benefits of exercise to reduce their risk of complications from surgery or providing them with worst-case scenarios, patients may be sceptical of such an approach if they form the belief that exercise did not appear to stop them from becoming ill or that the worst-case scenario will happen to them. These practices, as reported by the nurses, contrasts with literature which suggested that gain-framed messages were more successful than loss-framed messages at achieving behaviour change (Gallagher & Updegraff, 2012; van 't Riet et al., 2010). As the findings from Chapters Four and Five demonstrated that people with bowel disease spoke of the positive benefits of exercise, gain-framed messages may help nurses manage the patient resistance to exercise that they experienced as explained in Chapter Six.

The nurses believed that they had a role to play in physical activity counselling for bowel disease patients, yet they were aware of the many deficiencies in their current practice. The findings from Chapters Five and Six highlighted that physical activity counselling was not currently a substantial part of patient care. This may result in poor patient outcomes as was demonstrated by the findings from Chapter Five. Hospitals may need better support structures in place for managing the multidisciplinary roles of staff potentially involved in physical activity counselling for people with bowel disease recovering from bowel surgery. Nurses may need further education and training in physical activity counselling to capitalise on their opportunity to encourage healthy behaviours, such as exercise, to their patients. Further work needs to be conducted to examine how nurses can best collaborate with surgeons and physiotherapists in this regard.

In order to provide effective physical activity counselling, it is important to explore the current activity counselling practices from the perspectives of the major stakeholders. In bowel disease care, further work is needed to ensure that people with bowel disease and members of their care team, in particular nurses, are provided with the

necessary resources to foster their physical activity counselling practices. This may be achieved through an exploration of the current government and hospital policies and procedures regarding physical activity counselling for the pre-operative and post-operative care of people with bowel disease. Additionally, further research may apply conversation analysis to physical activity counselling discussions between nurses and people with bowel disease. Through conversation analysis specific nuances relating to the definition of exercise and the phrases and terms around “exercise” may be understood further. Conversation analysis between other healthcare professionals and people with bowel disease would also add knowledge about the role of physical activity counselling among healthcare professionals. Future research with focus group discussions among key stakeholders regarding the healthcare professional(s) most suited to physical activity counselling should also be conducted. The addition of other healthcare professionals in exploring physical activity counselling for people with bowel disease may highlight other efficiencies and deficiencies within the healthcare system.

7.4 Limitations of this thesis

One limitation of this research is that it cannot be determined if the benefits of exercise experienced by the participants in this study are a result of exercise or the passage of time. Measures of QOL in bowel cancer survivors appeared to return to normative values four weeks post-operatively (Jensen et al., 2014). However, exercise provides many health benefits that are separate from preventing diseases and illnesses. Therefore, the benefits of exercise, regardless of time since diagnosis, were still beneficial in terms of improved physical and psychological factors associated with normal healthy ageing. Furthermore, as IBD is characterised by stages of remission and relapse, people with IBD appear to be continually impacted by their disease, suggesting that exercise and physical activity played a role in improving the lives of individuals with IBD. Additionally, participants in this current study described the positive benefits that exercise provided them concerning survivorship and disease management.

Another limitation of this overall program of research was that it was conducted by an outsider. In qualitative health research, an outsider is someone who does not work

in the health industry and is mostly unfamiliar with protocols and procedures relating to everyday practice in that industry. Outsiders, Morse (2010) argued, may find some of the settings in which qualitative health research takes place such as a hospital, uncomfortable and unnerving. It was also claimed that outsiders might produce unsophisticated findings and emphasise topics health professionals including nurses, or other medical staff, may find unimportant (Morse, 2010). However, an outsider perspective does provide many benefits to this research and qualitative health research as a whole. Being unfamiliar with standard protocols, such as hospital discharge processes, an outsider can take a more critical view of the process simply by being unfamiliar with it. For this thesis, being an outsider provided strengths to the findings because the focus of this research was around exercise and physical activity counselling, something familiar to the researcher. By exploring this familiar focus from an unfamiliar life world, a new perspective on clinical practice was developed.

7.4.1 Epistemological reflexivity

Each empirical study chapter addressed personal reflexivity and how this may have affected the research. It is also prudent to address reflexivity in a broader sense relating to the program of research as a whole. This will be addressed here.

According to Howitt (2010), epistemological reflexivity is an active reflection of the assumptions that have contributed to the view of this research and the research findings. This reflection in qualitative research answers questions relating to how the methods may have influenced the findings and the basic assumptions made by the researcher that contributed to the findings (Dowling, 2006). For example, this project assumed the definition of exercise would be similar across the participant groups. Following an inductive thematic analysis (ITA) of the online data and through semi-structured interviews with people with bowel disease, it became increasingly evident the definition of exercise varied quite extensively between participants. The findings from Chapter Six substantiated these results; and therefore, future research exploring exercise beliefs should provide a clear definition of what the term exercise means. Clarifying the term “exercise” for Chapter Five and Chapter Six by asking the participants to express

their own definition added greater insight into physical activity counselling because it created a focal point to which the interviewer could refer.

In light of the finding that the definition of exercise was varied across participants, the data collected during the semi-structured interviews relied heavily on the participants' definition. Therefore, how and the context within which physical activity counselling occurred, can only be understood from the perspective of the participants' definition of exercise. Furthermore, the semi-structured interviews limited what could be found about how physical activity counselling occurs and the experiences of those discussions. It is possible that many examples of physical activity counselling were not discussed within the interviews as the participants did not recognise those instances as a moment when physical activity counselling occurred. Therefore, the findings of this research programme are limited to the participants' perceptions of what establishes physical activity and exercise.

7.5 Development and summary of the thesis

This thesis has questioned how, and the context within which, physical activity counselling occurred among people with bowel disease. To determine the extent to which this thesis answered this research question, it is useful to review the development and summary of this thesis. While exploring the literature in Chapter Two, it became apparent that while there appeared to be evidence that supported the benefits of exercise for people with bowel disease, there was little information about the dissemination of this knowledge by healthcare professionals to people with bowel disease.

With further reference to the literature regarding methods and methodology in Chapter Three, it became clear that a new perspective of physical activity counselling was necessary. Therefore, Chapter Four conducted an inductive thematic analysis (ITA) of communication within an online support form as a means of exploring the role of exercise and physical activity for people with bowel cancer; one type of bowel disease. The chapter began with a literature review that explored online health discussions and qualitative research followed by a discussion of the cancer-specific online discussion group literature. The thematic analysis of the online interactions provided valuable

knowledge, such as the views with which some people with bowel disease held about the benefits of exercise, for future investigators and a source of themes that could be explored further in this thesis. Additionally, this chapter provided a deeper understanding of the challenges faced by people with bowel disease in regards to discussing physical activity with each other and members of their care team. Exploring interactions that occurred online achieved a unique perspective on the role of exercise and how people with bowel disease shared their experiences about exercise with each other. Investigating the online interactions first was a great benefit to the overall programme of research because it allowed the researcher access to the world views of people with bowel disease without interference or influence. Through observation of the interactions that occurred in a public space as the starting point of this thesis, a comprehensive understanding of how exercise was perceived and manifested itself in the lives of the forum members was realised and provided the framework on which formed Chapter Five. These descriptions, described in Chapter Four, not only identified exercise as a major component of living through bowel disease, but also highlighted the importance of exploring how information about exercise was shared in the healthcare setting.

To gain further insight into the patient's perspective regarding the benefits of exercise and to be able to probe into how they perceived physical activity counselling, Chapter Five utilised semi-structured interviews with 20 people diagnosed with bowel disease. Specifically, Chapter Five sought to gain an additional understanding of the value of exercise for individuals with bowel diseases, other than cancer, and to understand the experience of physical activity counselling from the patients' perspective. The background at the beginning of the chapter briefly discussed the benefits of exercise for people with bowel diseases followed by an exploration of the lived experience of exercise and physical activity counselling. The interviews provided a platform for people with bowel disease to express their beliefs regarding exercise and the experiences they had when discussing exercise with members of their care team. Analysis of the interviews generated themes including *exercise was a catalyst for patients to actively participate in governing health* and *the assumed positions taken by care teams about exercise affects participants experience*. This led to the understanding that physical activity counselling (or lack thereof) greatly influenced their personal beliefs about exercise in addition to

influencing their beliefs about the level of care they received. An awareness of the role of exercise and a solid foundation of understanding about the impact of exercise on the experience of disease and care was achieved through this study, and provided a further line of enquiry conducted in Chapter Six.

As highlighted in Chapter Five, physical activity counselling had the potential to influence the illness experience of people with bowel disease. Furthermore, to fully understand physical activity counselling among people with bowel disease, it was imperative to explore this phenomenon from the perspective of professionals who provided care to people with bowel disease. As it was previously demonstrated that people with bowel cancer and IBD might be treated surgically for their disease, it became evident that the healthcare professional group that should be interviewed were nurses due to the greater time they spend with patients' post-surgery compared to other healthcare professionals. Semi-structured interviews were conducted with 15 nurses who worked on the surgical ward of two different hospitals. The interviews with nurses provided a perspective into what physical activity counselling involves. Several key issues emerged from these interviews including *managing conversational expectations in relation to other healthcare professionals* and *managing patient resistance to engaging in exercise*. These findings emphasised the personal and managerial struggles nurses encounter in trying to provide physical activity counselling to their bowel disease patients.

This thesis makes substantial contributions to the exercise and bowel disease literature as well as to the broader literature surrounding health communication. These contributions include the relevance of exercise for people with bowel disease and the importance of care staff sharing exercise information with people with this disease. The findings also indicate that patients wanted information on not only the medical benefits, but also specific information on the wider overall health and well-being benefits of exercise and how to achieve these benefits. The fact that the absence of exercise counselling in care resulted in perceived poor patient experiences is something that should be addressed in future research to improve patient outcomes. This research highlights the value placed on physical activity counselling by people with bowel disease and the nurses who work in bowel disease care. Overall, this research can enhance the

understanding of the experience of care for people with bowel disease by assisting and augmenting bowel disease-specific physical activity counselling guidelines.

Appendices

Appendix A:	Chapter Four: Example of Theme Development
Appendix B:	Bowel Disease Participant Explanatory Information Statement
Appendix C:	Bowel Disease Participant Informed Consent Form
Appendix D:	Recruitment Flyer
Appendix E:	Bowel Disease Participant Interview Schedule
Appendix F:	Chapter Five: Example of Theme Development
Appendix G:	Nurse Explanatory Information Statement
Appendix: H:	Nurse Interview Schedule
Appendix I:	Nurse Informed Consent Form
Appendix J:	Chapter Six: Example of Theme Development

Thread #	Line #	phrase in text	initial note	initial codes	sub-theme	Provisional theme	Final Theme name
36	141-143	"And yes, even if it's just 5 minutes, putting those tennies on and getting on the treadmill is still a good thing. 5 minutes of exercise is more than nothing and it's good to get your breathing rate up and get that heart going. Sometimes the breathing rate needs to get up just to make us feel more alert."	still a good thing	trust		Trusting exercise to keep them healthy	Faith in their knowledge of the benefits of exercise
80	142	"to save my life I do 4 X 40 min a week of vigorous walking."	to save my life				
30	68-69	"In my research, again, the common denominator of people who successfully cured their cancer was yoga."	successfully cured their cancer				
58	19-20	So far it has been working but I still have three years to go before I am considered "cured". If anybody knows of anything else that I should be trying or if anyone is doing something similar I would appreciate your feedback. Thanks.	"cured"				
23	113-114	"Studies have shown longer survival with folks who exercised after cancer."	longer survival				
12	43-44	"Anything you can do to reduce stress, build up your immune system, and get sunshine and exercise is going to prolong your life, regardless of the cancer."	prolong your life				

			a jaded eye	disillusionment
7	81-83	"Thank you for an interesting item, I have to admit I look at these studies with a jaded eye now. I was exercising (brisk walking or swimming, strength training and yoga) regularly for years (20 or more) and eating my nine servings of veggies/fruit per day. My co-workers would make fun of me. I ate very little red meat (Once a month or less). Yet I still came done with stage 4 rectal CA."		
2	18-19	"I too was very active, walking 5 miles each morning, eating healthy - all the things I thought would keep me healthy - luck of the draw I guess."	all the things I thought would keep me healthy	
22	57-58	"I have exercised most of my life before (not much during) and after cancer. Even if it didn't help stop the beast, which I do believe it does, I would still do it."	it didn't help stop the beast	
57	18-19	My mom had never drank alcohol, never smoked anything, exercised regularly, maintained healthy eating (well as healthy as southerners can), no familial history of any cancer and she gets stuck at 58 with stage four colon cancer and died at 60. Sometimes it just ain't fair, is it.	just ain't fair	

EXPLANATORY STATEMENT

BUHREC Protocol Number: 1961

STUDY TITLE: What about exercise?
Investigating how patients with bowel disease
discuss physical activity

PRINCIPAL INVESTIGATORS:

Asst. Prof Sally Sargeant (PhD)
Bond University
07 5595 5645

A/Prof Justin Keogh (PhD)
Bond University
07 5595 4487

Alicia Olsen MSc
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ABN 88 010 694 121
CRICOS CODE 00017B

Who is doing this study?

Researchers from Bond University are conducting this study to gather intelligence on the exercise discussions people with bowel diseases are having with their nurses, specifically how they are initiated, conducted, received and acted upon.

Why are we doing this study?

Following an extensive review of the literature, there appears to be no published research on exercise discussions occurring between nurse and patient in bowel

disease care specifically. Additionally, there appears to be no published literature investigating the views people with bowel disease have on exercise and the value they place on exercise and physical activity.

How can you participate?

You can participate in this study if you are a person diagnosed with a colorectal cancer, ulcerative colitis or Crohn's disease over the age of 18.

Risks that you might experience

There is a very small risk of creating psychological distress and if so, counseling can be obtained through contacting your local psychologist or GP.

The expected benefits of the research

There is an abundance of literature suggesting that exercise is beneficial for people with bowel disease. However, *how* this information is being conveyed to patients is unknown as well as the value of exercise for people with bowel disease. How these discussions are initiated and the contexts in which they take place are important features relating to clinical conversations about exercise.

Your participation is voluntary

Your participation in the interview is voluntary. You may withdraw from the interview at any time. You will not need to explain why you have withdrawn

and this will not have any effect on your relationship with the researchers, the centre or any of the institutions involved.

All results are confidential

The information that you provide to the investigators during the interview is strictly confidential. A pseudonym will be used in place of your actual name. The list with names and pseudonyms will be kept in a safe place, and no information will be disclosed to third parties without your consent.

Questions/further information

If you have any questions about any part of this study, please contact the Faculty of Health Sciences and Medicine on 5595 5645 and ask to speak with Dr Sally Sargeant, listed under investigators on page 1.

The ethical conduct of this research

This research abides by the National Statement on Ethical Conduct in Research Involving humans. If you have any concerns with the ethical conduct of the research party, feel free to contact: Bond University Research Human Research Ethics Committee by phone on (07) 5595 4194 or email buhrec@bond.edu.au



Dr. Sally Sargeant

Principal Researcher

Alicia Olsen

Student Researcher

CONSENT SHEET

BUHREC Protocol Number: 1961

STUDY TITLE: What about exercise? Investigating how patients with bowel disease discuss physical activity

PRINCIPAL INVESTIGATORS:

Asst. Prof Sally Sargeant (PhD)

Bond University

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CRICOS CODE 00017B

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement will include an interview
- I have had the opportunity to ask questions about the research and am satisfied with the answers I have been given;
- I understand the risks involved;
- I understand there will be no direct benefit to me (that is, financial incentives etc) from my participation in this research;
- I understand that my participation in this research is voluntary;

- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time without penalty;
- I understand that I can contact the Bond University Human Research Ethics Committee on 07 55954194 or email buhrec@bond.edu.au if I have any concerns about the ethical conduct of the project;
- I understand this project will meet the National Statement on Ethical Conduct in Human Research (Privacy), at <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>; and,
- I agree to participate in the project.

Participant	Signature	Date
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Investigator 1	Signature	Date
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Colorectal Cancer Research

What about exercise? Investigating how patients discuss physical activity with relation to colorectal cancer recovery and survivorship

Who is doing this study?

Researchers from Bond University are conducting this study to gather intelligence on the exercise discussions colorectal cancer patients are having with their nurses.

Why are we doing this study?

Following an extensive review of the literature, there appears to be no published research on exercise discussions occurring between nurse and patient in colorectal cancer care specifically. The current literature mainly discusses a combination of cancer types, with fewer being breast or prostate cancer specific. Additionally, there appears to be no published literature investigating the colorectal cancer patients' views on exercise and the value they place on exercise and physical activity during their cancer journey.

How can you participate?

You can participate in this study if you are a colorectal cancer patient or survivor over the age of 18.

Contact Alicia Olsen for more info

aolsen@bond.edu.au

Your participation is voluntary

Participation involves a one-time telephone or face-to-face interview. The interview may last 30-60 minutes. Your participation in the interview is voluntary. You may withdraw from the interview at any time. You will not need to explain why you have withdrawn and this will not have any effect on your relationship with the researchers, the centre or any of the institutions involved.

The expected benefits of the research

There is an abundance of literature suggesting that exercise is beneficial for cancer patients. However, *how* this information is being conveyed to patients is unknown as well as the value of exercise for colorectal cancer patients/survivors. How these discussions are initiated and the contexts in which they take place are important features relating to clinical conversations about exercise.

Questions/further information

If you have any questions about any part of this study, please contact the Faculty of Health Sciences and Medicine on 5595 5645 and ask to speak with the study supervisor Dr Sally Sargeant.

Interview Questions



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CRICOS CODE 00017B

How do you feel the definitions of exercise and physical activity differ?

Can you tell me about a time you discussed exercise in relation to your disease with one of your nurses or other clinicians?

How did this discussion make you feel?

What was your perception of your clinician during these discussions?

How does your perception influence any future exercise discussions you may have with this person?

Does this person provide you with any references or materials?

Can you tell me about a time exercise has influenced your life?

Where do you see exercise for people with bowel disease headed in the future?

Patient #	Line #	Data Extract	initial notes	initial codes	Subthemes	Final Theme	Provisional Theme name
14	355-257	when I first got sick, I started looking up, trying to look up, diet and exercise online	I started looking	pro-active in clinical discussions		exercise helped to promote health	Exercise was a catalyst for patients to actively participate in governing personal health
2	167	you're not told about them unless you seek them out yourself	you seek them out yourself				
16	58	I think I was the catalyst	I was the catalyst				
3	170-171	I sought out a dietician and anybody that I could get that would help me recover	I sought				
2	120-121	that was probably me initiating the conversation and there was no set direction	me initiating				
4	41-43	when I just started moving, I just found that it made me feel better	I just started moving	pro-active in controlling QOL			
3	35	I wouldn't feel as sick	feel as sick				
1	116-117	By not doing all these things would make me more sick	By not doing all these things				
4	46-47	I don't know whether it was the right thing to do, but it made me feel better, I just did it	I just did it				

		I thought this might be the right way to go	I thought	
2	88-89	exercise at the very least just does make you feel better	makes you feel better	
19	57	I needed to be doing them because they were beneficial	they were beneficial	
13	72-73	felt a bit healthier in myself as a result of undertaking exercise	as a result of undertaking exercise	
9	346	way of dealing with depression is exercise	way of dealing	
19	60-61	I walk morning and night, also just to be fit and feel good normally	I walked morning and night	
9	268	given me a better quality of life	better QOL	
9	127	brought inner peace	inner peace	Mental clarity and mental goodness
2	53-54	when you're really focused on, it does take you out of your head and you're focusing on what you're doing	takes you out of your head	
21	37	it's probably more a mind thing than anything	more of a mind thing	
9	135	takes your mind away from the stress	takes your mind away	

EXPLANATORY STATEMENT

BUHREC Protocol Number: RO1651



STUDY TITLE: What about exercise?

Exploring the nurses' experience of discussing exercise and physical activity with colorectal cancer patients.

PRINCIPAL INVESTIGATORS:

Asst. Prof Sally Sargeant (PhD)

Bond University
07 559 55645

A/Prof Justin Keogh (PhD)

Bond University
07 5595 4487

Alicia Olsen MSc

Bond University
07 5595 4152

Who is doing this study?

Researchers from Bond University are conducting this study to improve our understanding about the possible discussions between colorectal cancer care nurses and colorectal cancer patients about exercise and physical activity, specifically how they are initiated, conducted, received and acted upon.

Why are we doing this study?

Following an extensive review of the literature, there appears to be no published research on exercise discussions occurring between nurse and patient in colorectal cancer care specifically. The current literature mainly discusses a combination of cancer types or focusing on breast or prostate cancer patients specifically. The “all types” of cancer literature suggests that oncology nurses are aware of the benefits of exercise for their cancer patients, that they are discussing exercise with their patients but that many barriers still exist. This suggests a need for more information about current practice of exercise discussions that occur between the nurse and the colorectal cancer survivor to highlight the insufficiencies.

How can you participate?

You can participate in this study if you are a practicing colorectal cancer care nurse. This includes any nurse who is involved in the care of colorectal cancer patients following surgical treatments. These include but are not limited to oncology nurses, nurse practitioners, advanced practice nurses and stoma care nurses.

Risks that you might experience

There is a very small risk of creating psychological distress and if so, counseling can be obtained through contacting your local psychologist or GP.

The expected benefits of the research

There is an abundance of literature indicating that exercise is beneficial for many groups of cancer patients. However, *how* this information is being

conveyed to patients is unknown. There seems to be less public discussion about the benefits of exercise for colorectal and then other (e.g. breast and prostate) cancer patients suggesting the colorectal cancer patient may be unaware of the potential that exercise can have in their recovery. This may mean the exercise discussions patients have with their nurse may be the first time they are hearing about the benefits of exercise for their cancer survivorship. How these discussions are initiated and the contexts in which they take place are important features relating to clinical conversations about exercise.

Your participation is voluntary

Your participation in this interview is voluntary. You may withdraw from the interview at any time. You will not need to explain why you have withdrawn and this will not have any effect on your relationship with the researchers, the centre or any of the institutions involved.

All results are confidential

The information that you provide to the investigators during the interview is strictly confidential. The interview will be transcribed verbatim and sent to you for your validation to verify all information in the transcript is accurate and your words, views, opinions, etc. have been presented correctly. You will have the opportunity to retract all or part of your interview if you wish to do so during the validation process. A pseudonym will be used in place of your actual name. The list with names and pseudonyms will be kept in a safe place, and no information will be disclosed to third parties without your consent.

Questions/further information

If you have any questions about any part of this study, please contact the Principle Investigators.

The ethical conduct of this research

This research abides by the National Statement on Ethical Conduct in Research Involving humans. If you have any concerns with the ethical conduct of the research party, feel free to contact:

Townsville Hospital and Health Service Human Research Ethics Committee on (07) 4433 1440 or email tsv-ethics-committee@health.qld.gov.au

Bond University Research Human Research Ethics Committee by phone on (07) 5595 4194 or email buhrec@bond.edu.au

Interview Schedule



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What is your definition of exercise?

What is your definition of physical activity?

Describe to me an exercise discussion you have with your bowel disease patients following surgery?

How would you say these discussions are generally perceived by your patient?

How does your perception influence your discussion with current and future bowel disease patients?

What kinds of follow up questions do they ask?

How do approach the dismissive patients?

What sort of references do you use?

To whom do you normally discuss physical activity with?

What are their characteristics?

What are some characteristics you look for or use to determine who you discuss physical activity with?

Where do you see exercise for bowel disease patients and survivors headed in the future?

What role do you see exercise having in the experiences of bowel disease?

CONSENT SHEET

BUHREC Protocol Number: RO1651



STUDY TITLE: What about exercise?

Exploring the nurses' experience of discussing exercise and physical activity with colorectal cancer patients.

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- I understand the risks involved;
- I understand there will be no direct benefit to me (that is, financial incentives etc) from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time without penalty;
- I understand that I can contact the Bond University Human Research Ethics Committee on 07 55954194 or email buhrec@bond.edu.au or

Townsville Hospital and Health Service Human Research Ethics Committee on (07) 4433 1440 or email TSV-Ethics-Committee@health.qld.gov.au if I have any concerns about the ethical conduct of the project;

- I understand this project will meet the National Statement on Ethical Conduct in Human Research (Privacy), at <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>; and,
- I agree to participate in the project.

Participant	Signature	Date
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Investigator 1	Signature
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Nurse #	Line #	Data Extract	Initial notes	Initial codes	Subthemes	Provisional theme	Final theme name
6	218-219	"You sometimes need to be cruel to be kind. Some people need more coddling than other ones."	cruel to be kind	tough love		handling resistance from patients	Managing Patient resistance to engaging in exercise
3	91-93	They do it in such a sneaky way. It's actually very impressive. I'm not sort of that nasty, but sometimes, you know we have to be firm."	firm				
4	96-97	"Sometimes you have to be a bit forceful. You've got to go in and basically repeat yourself several times."	forceful				
7	77-79	You do need to be firm. Some you just need to lay down the law. You must get up and walk. You've been laying in bed all day. It's not good for your recovery. You need to get up now and do one lap of the ward with me. Let's go."	need to be firm				

13	102-106	"This continues with education and helping them and then basically getting to the point where you're like you have to get up, we are taught very early on that they can't just lay in bed all day we need to get them moving so that's probably when you have to put your foot down a bit more and go "no, this has to happen."	put your foot down
9	152-155	"When you've got everyone telling you, not just one physio, because a lot of people don't like the physios just because they make them do things when they don't and to or when they're tired. I really think it helps that you've got people backing them up"	everyone telling help from others
5	245-246	"The more people that say it, the more it will probably sink in."	power in numbers
8	19-20	"I just say, it's for your benefit, it will help you in the long run and it will help you speed your recovery as well"	your benefit trying to encourage patient responsibility
5	168-169	"you've really got to push and encourage to get them back going, even just doing simple things for themselves."	got to push

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